

**Exploring the implementation of
a community health worker programme for maternal and child health in the
rural Eastern Cape, South Africa**

By

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Declaration

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Abstract

Community health worker (CHW) programmes are regarded as important solutions for improving health care services and outcomes for mothers and children globally. In low- and middle-income countries (LMICs), CHWs may be able to bridge widening gaps between limited human resource capacity and population health needs. However, despite the expansion of CHW programmes, we lack evidence for their effectiveness at scale. Even well-researched evidence-based programmes, when brought to scale, tend to lose some of their effectiveness. Implementation science methods have emerged as one way to investigate why programmes succeed or fail, by providing researchers with frameworks to examine processes related to delivery, quality, and context. In this dissertation, I explore the processes underpinning the delivery of a CHW programme in rural South Africa.

This study addressed four related research questions, focused on CHW fidelity to training, client responses to and engagement with the programme, and contextual aspects that affect the programme's delivery. I utilised a combination of data sources, including transcripts from audio recordings of CHW home visits (n=84), interviews with clients of the programme (n=26), and interviews with CHWs themselves (n=10).

The findings of this study identify programmatic strengths, with high levels of fidelity to training in communication skills; instructive and mutually supportive relationships between CHWs and their clients; and dedicated CHWs who regularly prioritise their clients' needs. These findings also echo persistent challenges in programme implementation, including occupational burdens and pressures for CHWs, and barriers for clients in linking to health care within an under-functioning health system. This dissertation points to the importance of continued training, client and community consultation, and identification of contextual challenges to make programme

implementation more effective before they are able to be scaled. It also emphasises the need to adopt a human-centred approach to designing and implementing CHW programmes, shifting away from a technical, vertical mode of providing much-needed services.

Opsomming

Gemeenskapgesondheidswerkers (GGW) programme word beskou as 'n belangrike oplossing vir die verbetering van gesondheidsorgdienste en gesondheidsuitkomstes vir moeders en kinders wêreldwyd. In lae en middel-inkomste lande (LMIL'e) kan GGWs in staat wees om breë gapings tussen beperkte menslike hulpbronskapasiteit en bevolkingsgesondheidsbehoefte te oorbrug. Ten spyte van die uitbreiding van GGW programme, het ons steeds 'n tekort aan bewyse vir die effektiwiteit daarvan op skaal. Selfs deeglike nagevorsde bewysgebaseerde programme, as dit op die skaal gebring word, is geneig om hul doeltreffendheid te verloor. Implementeringswetenskaplike metodes het na vore gekom as 'n moontlike manier om te ondersoek waarom programme slaag of misluk. Hierdie implementeringswetenskaplike metodes voorsien navorsers met die raamwerke om die prosesse wat verband hou met die lewering, kwaliteit en konteks van die program te ondersoek. In hierdie proefskrif ondersoek ek die prosesse wat onderliggend is aan die lewering van 'n GGW program in landelike Suid-Afrika.

Hierdie studie het vier verwante navorsingsvrae wat gefokus is op die getrouheid van GGW aan opleiding, die reaksie van kliënte op die program, die betrokkenheid van kliënte by die program, en kontekstuele aspekte wat die lewering van die program beïnvloed. Ek het 'n kombinasie van databronne gebruik, wat transkripsies van klankopnames van GGW-tuisbesoeke (n=84), onderhouds met kliënte van die program (n=26), en onderhouds met GGWs self (n=10) insluit.

Die bevindinge van hierdie studie identifiseer programmatiese sterk punte, met hoë vlakke van getrouheid aan opleiding in kommunikasievaardighede; leersame en wedersydse ondersteunende verhoudings tussen GGWs en hul kliënte; en toegewyde GGWs wat gereeld hul kliënte se behoeftes prioritiseer. Hierdie bevindinge weerspieël

ook die aanhoudende uitdagings met die implementering van programme, insluitend beroepslaste en druk op GGWs, en hindernisse vir kliënte om te skakel met gesondheidsorg binne 'n onderfunksionerende gesondheidstelsel. Die proefskrif dui aan die belangrikheid van aanhoudende opleiding, konsultasie met kliënte en gemeenskappe, en die identifisering van kontekstuele uitdagings om die implementering van die program meer effektief te maak voordat dit opgeskaal kan word. Dit beklemtoon ook die noodsaaklikheid om 'n mensgesentreerde benadering in die ontwerp en implementering van GGW-programme toe te pas en om weg te beweeg van 'n tegniese, vertikale manier in die lewering van noodsaaklike dienste.

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Glossary of terms

Note: This glossary briefly summarises commonly-used terms in this dissertation, which are defined as they are used in this work. Definitions will be referenced as appropriate as the terms are introduced.

Client	Refers to individuals who are receiving services from the Enable Mentor Mother Programme. At times, and elsewhere, this term may be used interchangeably for beneficiary, recipient, or patient.
Context	As defined by the UK Medical Research Council, this refers to anything external to the intervention that may act as a barrier or facilitator to its implementation.
Community health worker	Refers to a diverse cadre of health workers, who are typically based in the communities in which they live and who respond to local health needs. These individuals usually undergo limited training; they may be volunteers or paid a small stipend; and they may be deployed by government as well as non-governmental organisations. Also known as a lay health worker.
Enable	The short name for the Enable Mentor Mother Programme, and is used throughout this dissertation.
Fidelity	In implementation science, this term is often used to identify if an intervention is being implemented as intended. This covers how “faithful” to the original model or aims the implementation efforts are.
Health care access	Refers to both an individual’s ability to reach health services and benefit from them when needed, as well as a system’s capacity to cater for individual needs.
Implementation science	The study of methods and factors that affect the uptake of health-related interventions into routine practice.
Maternal and child health	Knowledge and services related to antenatal and postnatal care, labour and delivery, maternal nutrition and infant feeding, immunisations, and infant development. In the South African context, this area of health also includes a focus on HIV and prevention of mother-to-child transmission, as well as other co-morbidities. It is also known as maternal, neonatal, and child health.

Positive deviant model	A theory guiding the selection of community members for CHW roles. Even in adverse circumstances, there are outliers (“positive deviants”) who are able to rely on less commonly used strategies to achieve successful outcomes. This term specifically relates to mothers who are able to raise healthy children in resource-limited settings.
Process evaluation	The study of interrelated processes, or practices, that comprise an intervention as it is implemented and evaluated. These may include aspects such as implementation dosage, delivery mode, and contextual factors that may influence outcomes.
Programme	The term I use to refer to community-based health initiatives throughout this dissertation. Programmes may refer to CHW initiatives led by non-governmental organisations, but may also refer to those under governmental health system supervision.
Social franchising	The replication of an evidence-based service delivery model in a new setting, under new management. It may or may not draw on support from the originating organisation or model, and aims to expand social impact. It is also referred to as a social franchise or the social franchise model.

Abbreviations used

AIDS	Acquired immunodeficiency syndrome
ASHA	Accredited Social Health Activist
CHW	Community health worker
DOT	Directly Observed Therapy
HIV	Human immunodeficiency virus
HCSI	Home Visit Communication Skills Inventory
ILCHR	Institute for Life Course Health Research
LMIC	Low- and middle-income country
MCH	Maternal and child health
MDGs	Millennium Development Goals
MM	Mentor Mother
MRC	Medical Research Council (UK)
NGO	Non-governmental organisation
PID	Participant identifier
RCT	Randomised controlled trial
SDGs	Sustainable Development Goals
WBOTs	Ward-based outreach teams
WHO	World Health Organization

Chapter 1: Background and literature review

Despite a global push to reduce disparities in maternal and child health outcomes, the most vulnerable women and children are still unable to access the services and care they need most to survive, and thrive (Kinney et al., 2016). One of the reasons for these poor outcomes is a crisis in human resources available for health, especially in low- and middle-income countries (LMICs), given widening gaps between the demand for necessary health care and the resources and personnel available to provide these services (Chen et al., 2004). Community health worker (CHW) programmes have long been a cornerstone of health systems in low-resource settings (Lehmann & Sanders, 2007). In the era of the Sustainable Development Goals (SDGs), these initiatives have again emerged as a promising solution to meet the needs of vulnerable populations, responding to current global goals (Schneider et al., 2016; World Health Organization, 2018a). However, the ability of CHW programmes to activate necessary, transformative change in maternal and child health care is still unclear. Within the vast literature on CHW programmes, little research specifically focuses on what factors might make them effective on the scale that is required to improve the health of women and their infants on a broad level.

Global health initiatives introduced over the past three decades have prioritised reproductive, maternal, newborn and child health, resulting in impressive progress towards reducing mortality and morbidity for millions of women and their children (Bhutta & Black, 2013; Chopra et al., 2009). At the same time, health inequities are vast. Increasingly more women suffer from severe maternal morbidities, especially in LMICs (Geller et al., 2018), and geography and resource distribution still dictates in large part whether children will live past their fifth birthdays or reach their full developmental potential (Spencer et al., 2019). Persistent poverty is one clear reason for this sustained

crisis in maternal and child health, shaping the environments in which women can make decisions about their own health and the health of their children. Structural factors, including infrastructure, available and affordable transport (Atuoye et al., 2015), distance from facilities (Kenny et al., 2015), facility resources, and household vulnerability may influence women's ability to access necessary care (Puett et al., 2015). On an individual level, health education levels, social and family influences, and gender norms may also drive how, when, and with what frequency pregnant women or mothers access care (Binder-Finnema et al., 2015; Kifle et al., 2017; Munguambe et al., 2016; Scheffler et al., 2015).

At the same time, a human resource crisis in health care in LMICs drives the quality of care prospective patients can expect to receive. There are simply not enough skilled professionals to meet the demand for services, and in the poorest countries, these individuals tend to be inequitably allocated, inadequately compensated, and overburdened (Chopra et al., 2008). These human resource shortages, across LMICs in all regions, have been found to lead to poor quality care for maternity patients (Gerein et al., 2006; Mannava et al., 2015; Srivastava et al., 2015). Research with health providers, especially in poorer rural areas, has documented their experiences of isolation, resource scarcity, and demotivation, with few opportunities for skills development (Melberg et al., 2016; Thi Hoai Thu et al., 2015). However, punitive experiences and mistreatment by overstretched providers further disrupt the potential for strong relationships and trust within the health system (Adatara et al., 2019; Bohren et al., 2019). Community-based health initiatives, often incorporating CHWs, present an appealing solution to this ongoing challenge.

A brief history of CHW programmes

At the core of CHW programmes is a promise of individual- and community-owned health services that can reduce the burden on strained and fragile health systems (Glenton et al., 2013). Historically, the concept of community health work is grounded in principles of health equity and empowerment. The Alma-Ata Declaration of 1978 laid the foundations for the global promotion of CHW programmes (Rifkin, 2018). It brought a focus to community health initiatives that had been specifically designed to reduce social and geographical inequities in health care (Mhlongo & Lutge, 2019). Building off of successful initiatives in China, India, and Tanzania, Alma-Ata proposed CHW programmes as a means to prioritise primary, preventative care, and thus reduce health care costs while bolstering population health. The ensuing scale-up of comprehensive programmes—by governments and non-governmental organisations (NGOs) alike—was built on a premise of increasing health equity, mobilising communities, and empowering people living in poverty (Perry et al., 2014).

However, despite the conceptualisation of CHWs as agents of change within their own communities (Colvin & Swartz, 2015), the scalability of these programmes was soon questioned. Comprehensive community health initiatives proved to be costlier, and more burdensome to implement and oversee, than originally envisioned (Christopher et al., 2011). In countries adopting bold development agendas, CHW programmes also became enmeshed in debates around health financing and strategy over the long term—thought to promote a sub-standard, “second-rate” quality of care. Consequently, many countries opted to do away with these programmes or made them increasingly more selective and technical, utilising international expertise and funding (Baum, 2007; Perry et al., 2014). Such focused or “vertical” programming for CHWs often targeted the most pressing health need in a given area or country, and momentum built around responding

to maternal and child health needs. Child growth, oral rehydration for diarrhoea, breastfeeding, and immunisations became widely seen as cost-effective priority health areas across many LMICs (le Roux et al., 2014; Walsh & Warren, 1980), as these disease-specific interventions were viewed as able to deliver greater returns (Magnussen et al., 2004). CHWs were also effectively utilised to assist with directly observed therapy (known as DOT) for tuberculosis at the community level (Wilkinson & Davies, 1997). This approach required a limited, technical skill set in one health area or a set of interlinked areas, which CHWs could be trained to fulfil, and also relied little on functioning in-country health systems.

By the early 2000s, ideas about how to operationalise CHWs had again changed, with a new interest in improving global health fostered by the Millennium Development Goals (MDGs), and made more urgent by the expanding HIV/AIDS epidemic (Kredo et al., 2014). This move was marked by a more concerted effort towards elevating the roles of CHWs, responding to widespread fragmentation by integrating them into existing health systems and creating policies that focused on channels for CHW programme sustainability (Tulenکو et al., 2013).

Concurrently, on a practical level, task-shifting emerged as a way to systematically reallocate essential tasks, which required little training to complete, from professional health workers to CHWs (Lehmann et al., 2009). Although the concept of task-shifting had long been practised in low-resource settings, it gained new recognition as a strategy to make health services more efficient (Seidman & Atun, 2017). As CHWs have taken on an increasing number of roles, their scope has become more expansive (Swider, 2002). Consequently, ideas about using CHWs to advance goals of health equity have often been lost in the attempt to deploy these workers to meet more immediate needs.

The embrace of a comprehensive, broadly tasked cadre of CHW is, in many ways, closer to the original conceptualisation from Alma-Ata. The Declaration of Astana, emerging from the 2018 Global Conference on Primary Health Care in Astana, Kazakhstan—which coincided with the 40-year anniversary of Alma-Ata—reiterated the need to prioritise sustainable primary health care and identify pathways to inclusive, accessible, and equitable health care for all (World Health Organization, 2018b). However, as tasks for CHWs accumulate, and as they are flexibly applied to fit diverse societal needs, CHWs may also struggle under undue burdens (Dambisya & Matinhure, 2012). Their ability to meet the health needs of a given population relies on their natural skills, the way they are selected, the training they undergo and resources they are equipped with, their individual motivation and orientation towards the role, and the sustained support they receive as they conduct their work (Mundeva et al., 2018).

Defining CHW roles

One of the most evident challenges CHW initiatives continue to face is a lack of clarity around role definition (Olaniran et al., 2017). CHWs, sometimes referred to as lay health workers or paraprofessionals, are typically front-line health workers—responsible for carrying out preventative health interventions that can help reduce the burden of disease in vulnerable populations through education and the identification of health needs, often in a decentralised way (World Health Organization, 2018a). CHWs can help bridge gaps between prospective patients and the formal health care system, providing simple yet valuable interventions at the household and community level (Scott et al., 2018).

However, their focus areas and the ways in which they are deployed vary significantly (World Health Organization, 2018a). CHWs may be employed by the

government (e.g. Departments of Health) to work within primary health facilities or in communities conducting outreach work in people's homes, or some combination of both (Herman, 2011). They may also be employed by NGOs or agencies. For the latter, programmes often communicate and/or coordinate services with the formal health system to function more effectively (Haines et al., 2007). As such, CHWs have tended to function as extensions of formal health care systems. CHWs tend to be community members without formal education or extensive employment history, who undergo role-specific training over a period of weeks or months (Lehmann & Sanders, 2007). They typically deliver services in the areas in which they live or are from, and are typically, but not always, paid a small stipend. The majority of CHWs are also women, who may be assumed to be natural carers, yet who face additional social expectations of care work in their own personal lives (Daniels et al., 2012; George, 2008).

Because their roles often bridge clinical and social domains, CHWs may be able to take time with clients to provide personalised care in a way that formal health systems cannot (Nxumalo et al., 2016). The home visit setting is particularly conducive to this approach. However, CHWs in many settings also face ambiguity in their roles, with difficult working conditions, and non-standardised supervision structures and working policies (Daniels et al., 2012; Trafford et al., 2017). As a cadre, CHWs are seen as vitally important, and yet not well-defined; this flexibility in role and scope can make it challenging to understand their impact, while also tempting to cast them as potential “solutions” to numerous entrenched health issues.

Generating evidence for CHW programmes

As CHW programmes have gained momentum in global health policy agendas, there has been an increasing demand for evidence on if and how CHW programmes

work, and a desire to generate evidence- and data-driven ways of responding to social and health disparities. While there is a general consensus that CHW models should be implemented in a way that best serves the population and context in which they operate, there is a need to better understand which “best-practice” models hold promise for being scaled and replicated across a diverse range of settings (Pallas et al., 2013).

Often, public health prevention programmes follow a continuum of steps from idea to scale-up. These programmes should be driven by theory, as well as based on prior epidemiological and social research (Olds, 2002). Testing these programmes requires significant resources, as well as a long-term vision to design, pilot-test, refine, implement, and expand a specific programme. Flay and colleagues, part of the Society for Prevention Research, set out Standards of Evidence for prevention models to progress from efficacy, to effectiveness, and finally dissemination, with clear, specific targets laid out at each step (Flay et al., 2005). Efficacy studies are conducted within controlled settings, testing interventions in a randomised design and identifying positive outcomes through at least one long-term follow-up data point. Effectiveness studies, one level more developed, test the idea more clearly in a “real-world” setting. For an intervention to be ready for dissemination, it must meet all of the above criteria, with an additionally evidenced “path to scale,” cost effectiveness data, and criteria for monitoring and evaluation. Somewhere between effectiveness and dissemination, a “franchise” might form an intermediary step, where programmes are transported to new places and tested, but not yet disseminated on a broader scale (Penn-Kekana et al., 2018).

With CHW programmes, this drive for a best-practice, evidence-based approach has resulted in a multitude of individual programme evaluations that provide substantial evidence of the promise of these models in improving maternal and child health (Gilmore & McAuliffe, 2013; Haver et al., 2015; Olds et al., 1986; Rotheram Borus et

al., 2011). Randomised controlled trials (RCTs) assessing specific health-related outcomes have been identified as central to understanding in what areas, and to what extent, these kinds of programmes are having desired impact on population health (Lewin et al., 2010). Trials are also effective vehicles for conveying these findings to donors or government officials responsible for allocating funds to sustain such programmes. However, despite the pretext of creating evidence that might be collectively utilised and replicated, many community health programmes have remained tightly controlled. In certain cases, the evidence for these programmes' effectiveness may arise from internally-conducted evaluations, posing potential conflicts of interest (Eisner, 2009). From a more pragmatic perspective, efficacy studies may also be substituted for "evidence" even when the programme effects can only be demonstrated in highly-controlled environments (Hodgins et al., 2013).

While efficacy studies may be necessary at the early stages along the life course of an idea, exploring factors related to the programme's processes and implementation is a crucial step in translating research-based findings to real-world, practical dissemination (McKay et al., 2004). As CHW programmes expand—adopted and brought to scale by governments and NGOs alike—they tend to lose some of their effectiveness (Olds et al., 2003). Implementation science as an emerging health-related discipline offers a roadmap to understanding why this shift happens (Bauer & Kirchner, 2020). These factors may lie within domains of quality, programmatic fidelity, delivery mechanisms, and beneficiary responses (Kim et al., 2015; Moore et al., 2015; Rifkin, 2018). An implementation focus also encourages researchers to consider contextual and systemic factors that influence a programme's success, aspects that have been overlooked in previous work (Blacklock et al., 2016; Kegeles, 2015). Interestingly, many of the domains that are prioritised within an implementation science framing are those that have been neglected in the global

literature on CHW programmes, including training and fidelity. These methods facilitate a more critical appraisal of CHW programmes, to help understand why they struggle to reach scale effectively and where improvements may be warranted.

Identifying gaps in programme evidence

A stronger understanding of how programmes evolve requires a broader set of evidence—and a more comprehensive set of methods—to document the move from effectiveness to scale through a “franchise” step, and to make these programmes more viable across diverse settings. It also requires a clear sense of where gaps exist, accompanied by evidence, as to why programmes may fail to go to scale.

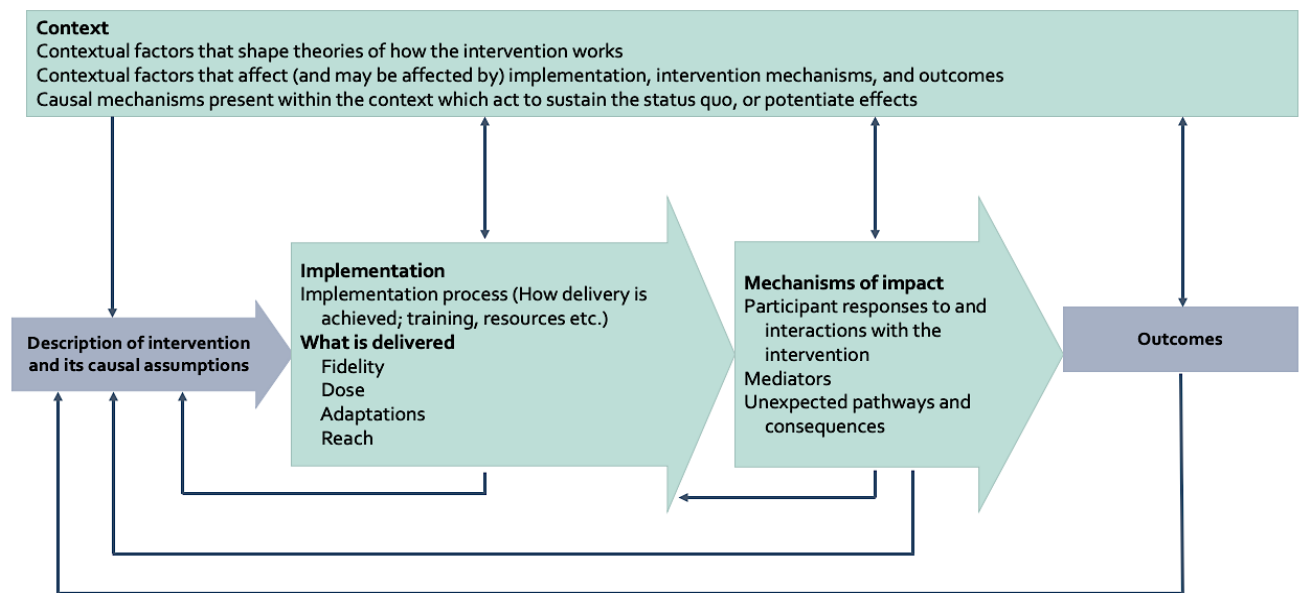
One useful organisational framework for understanding diverse processes within programmes, and how they relate to one another, is the process evaluation framework for complex interventions designed by the UK Medical Research Council (MRC) (Moore et al., 2015). It is reproduced in Figure 1 below.

The framework accounts for interactions among implementation, mechanisms of impact, and context.

- **Implementation** encompasses the structure, resources, and processes that contribute to an intervention’s delivery. Implementation includes human resources as well as provisions for programme delivery. It accounts for the quality and quantity (i.e., “dosage”) of what is delivered, as well as the fidelity of implementation to the intended intervention.
- **Mechanisms of impact** encompass how intervention activities and participant responses to these activities interact to create change.

- **Context**, or external factors, can affect the feasibility of delivering an intervention in a given place, and can also determine how readily the intervention will be accepted by its intended beneficiaries (or not).

Figure 1: Overview of MRC framework



Reproduced from Moore et al., 2015.

These three core domains help to frame significant gaps in the evidence underpinning CHW programmes, to which I will respond in this dissertation.

Implementation fidelity

Firstly, fidelity is an important but under-researched area in implementation of CHW programmes. Despite an emphasis on selecting and training talented community members to fulfil essential roles as CHWs, there is limited follow-through on skills and competencies after pre-service training is complete. Establishing fidelity to a programme model and training can entail understanding the degree to which core content is being

delivered as intended, and core practices are being employed as intended (Dunst et al., 2013). The monitoring and evaluation protocols that tend to be implemented in CHW programmes skew towards fidelity of content over practice (Schodt et al., 2015). Even when practices are monitored, however, certain types of routine data—such as client visits completed, or referrals to health facilities initiated—are prioritised. These data provide links between training and performance “in the field,” and are often relatively easy to quantify. However, it is important to distinguish between adherence and competence in measuring fidelity to practices. Whereas adherence measures *whether* a practice or activity has been implemented, competence measures *how well* it is done; it includes communication, skills, and abilities that may affect how the intervention can be delivered (Breitenstein et al., 2010). Because competence may be seen as a “soft” skill or set of skills, one that is less easily measurable, it is often overlooked in evaluating CHW performance following training.

CHWs themselves may recognise a need for more concerted skills development and capacity-building (Allen et al., 2016), and some programmes adopt opportunities for in-service training, and utilise routine meetings as a place to refresh knowledge and teach new skills (Abdel-All et al., 2019). However, in more resource-stretched programmes, these kinds of platforms for continuing monitoring quality and promoting role-specific and professional development may not exist. Because softer skills rely on more time-intensive supervision or structured ongoing training, they tend to be taken for granted (as natural abilities present at the time the CHW was chosen) or neglected in favour of more easily measurable markers of success (as less valuable to donors than tangible numbers).

Mirroring programmatic practice, research about CHWs lacks a closer examination of these competencies as they evolve, or deteriorate, on the job (Tseng et al., 2019). While different types of performance and quality monitoring have proliferated

in clinical settings—such as performance checklists—these kinds of considerations, and the tools to measure them, have been largely absent from CHW settings, especially in LMICs (Dorsey et al., 2018). In bolstering implementation data from CHW programmes, a more comprehensive approach to measuring fidelity to training over a longer time horizon, specifically around skills and implementer competence, is needed.

Participant responses to the intervention

Secondly, understanding how participants respond to CHW programmes is critical for measuring potential mechanisms of impact, but this practice often neglected. Many CHW programme evaluations do not engage their clients in the implementation of the programme. Overall, the clients who are beneficiaries of these programmes are economically, socially, ethnically, or geographically marginalised (McCollum et al., 2016; Swartz & Colvin, 2015).¹ Despite research that highlights client preferences or utilises community engagement strategies to increase buy-in, research about how clients experience and respond to these programmes is limited (Bain et al., 2017; Roman et al., 2012). More specifically, while programmes often teach CHWs to connect with clients on an individual basis, and to incorporate client preferences and experiences within the context of the relationship, few programmes are structured around collecting and examining client feedback about the broader programme (Wallerstein & Duran, 2010).

These perspectives may provide a more nuanced, comprehensive understanding of mechanisms by which CHW programmes are taken up when moved to new settings. Feedback from programme clients and their families throughout the course of the

¹ In this dissertation, I refer to these individuals and families as clients. I use this term to apply a uniform understanding of these individuals as engaging in an ongoing relationship in the context of the intervention (rather than simply receiving, or benefitting from, an intervention). I also seek to differentiate these client-CHW relationships from traditional therapeutic or clinical relationships between health providers and patients.

programme's implementation can be used to help shape training curricula for CHWs so that they respond to clients' needs (Kangovi et al., 2016; World Health Organization, 2016). These perspectives can also illuminate reasons for participant engagement or dropout, giving programme implementers a stronger sense of what works, in which circumstances, for what type of client, and affecting an overall theory of change for a programme (Grant et al., 2017; Perales et al., 2018). Clients may also convey vital information that enables CHWs or their supervisors to make interventions more locally relevant, especially if programmes have been adapted or transplanted from other settings (Isler et al., 2019; Lachman et al., 2016). Therefore, the success of CHW interventions may rely on healthy relationships with clients. Because little evidence has been gathered about how clients respond to and engage with these interventions and with their CHWs, client perspectives in process and outcome evaluations are much needed.

Contextual factors that affect implementation

Finally, much of the existing research does not adequately account for contextual influences surrounding the programme—ignoring information that may significantly alter the way programmes can be delivered. While evidence-based models provide a standard blueprint for how services or health education should be delivered, it is also generally accepted that CHW programmes must be specific to their contexts (Scott et al., 2018). Many CHW programmes are premised on realities of cultural and social similarity that present CHWs as peers but also trained individuals. They may be able to connect better, and respond better, to their target clientele (Azzi-Lessing, 2013). However, there is a fundamental tension between maintaining the integrity of high-quality, evidence-based interventions while also acknowledging that CHW programmes in LMICs often need to adapt to accommodate specific contextual realities. These

contextual realities may include, among other areas, the experiences of implementers in delivering an intervention in a given community, and the way in which clients are able to follow through on new knowledge and facilitated linkages to care (Blacklock et al., 2016; Moore et al., 2015). These specific considerations shape the extent to which CHW programmes are able to translate to new settings effectively (Kok et al., 2015).

The experiences of CHWs, as implementers of a programme and curriculum, are often focused on within-programme experiences. These accounts include perspectives on training (Allen et al., 2016), supervision (Kok et al., 2018), and knowledge (Suri et al., 2007). However, CHWs also face challenges related to the communities and environments in which they operate, and their role involves a process of navigating between their jobs and their identities as community members (Maes et al., 2014). The process of differentiating these roles and leveraging community familiarity to create bridges and generate buy-in is essential—and part of understanding and accounting for the context in the implementation of a CHW programme. On a broader level, CHW programmes are also nested within existing community structures, subject to a set of expectations from those who will be participating and benefitting from the intervention (Lehmann & Gilson, 2012). Furthermore, CHW programmes, and their implementers, operate within larger existing health systems in a given district, province, or country, and these systems may affect, or be affected by, CHW programmes' operations (Kok, Broerse, et al., 2017; Seidman & Atun, 2017).

Clients' ability to engage with the intervention in their broader environment is also linked to context. Barriers to programme uptake and behaviour change may include accessibility, availability, and adequacy of formal health care services (Scheffler et al., 2015), as well as more individual or environment-linked challenges such as limited access to transport funds, or household disagreements about infant feeding. Existing

studies rarely recognise these types of factors in measuring effectiveness (Nxumalo et al., 2013). Much of the research that does attend to context-related factors explores these issues among patients outside the context of CHW programmes (Kifle et al., 2017; Neely & Ponshunmugam, 2019). Other research lists these contextual challenges, rather than considering individuals and their contexts as part of a dynamic system.

Considering these domains in framing evidence gaps

Without careful attention to these process factors, evaluations and examinations of CHW programmes may overlook critical aspects of implementation, risking repeating the same mistakes as new programmes are implemented and taken to scale. In order to focus efforts to understand how these areas affect CHW programmes as they are implemented, it is important to apply this theoretical understanding of implementation to practical, “real-world” programmes.

Current research needs to focus on programmes operating in diverse settings in addressing these broader gaps in the evidence about CHW programmes. In rural South Africa—the site of my dissertation—these challenges are particularly pronounced, and evidence from CHW programmes is limited. Before introducing the study rationale and research aims, I provide a brief overview of CHW programmes in South Africa.

CHW programmes in the South African context

The trajectory of CHW programmes in South Africa has mirrored global trends while also responding to a distinct set of historical and political forces (Coovadia et al., 2009). During the height of the apartheid era, in the 1970s, many CHW programmes were operationalised by non-state actors to attempt to provide more equitable care to populations living in the “homelands,” whose health care budgets were under-allocated

and often misappropriated (van Ginneken et al., 2010). Emergent CHW programmes were often vertical, focused on preventing communicable diseases (Mhlongo & Lutge, 2019). Many of these programmes were also decidedly political in nature: even where the programmes' founders projected a neutral stance, CHWs, who were mostly black women, were able to adopt roles that directly challenged the restrictive and unequal climate of apartheid (Trafford et al., 2017; van Ginneken et al., 2010). Programmes were often forced to be creative, adaptable, and responsive to community needs, and experienced little oversight from funders, many of whom were based overseas.

From the mid-1990s, as South Africa transitioned to a new democratically elected government, the political nature of CHW programmes shifted (Schneider et al., 2008). South Africa's constitution established a universal right to health care, founded on principles of equity in care (Ngwena, 2000). Part of this mandate included a concerted move away from CHW programmes. These programmes were absent from the new national health policy, replaced by a vision of professional health teams of doctors and nurses—echoing similar decisions that had been made in other nations, and neglecting lessons from existing, successful programmes (van Ginneken et al., 2010). Newly-reinforced hierarchies, as well as lack of clarity around roles, generated conflict between nurses and CHWs (Doherty & Coetzee, 2005), which would have lasting impact on how communities received CHWs and how their roles were recognised and valued.

This newly conceived health system was thrown into flux with the onset of the HIV/AIDS epidemic, which hit South Africa with particular force and required a new cadre of lay workers to mobilise grassroots public health efforts (Coovadia et al., 2009). CHWs, as home-based carers or adherence support counsellors, were deployed to assume specific roles to support HIV patients and connect them to care (Schneider et al., 2008). The depth of challenges facing South Africa in the first decade of democracy—the

HIV epidemic, persisting social, economic, and racial inequalities, and challenges with health provision and accountability—revived public interest in CHWs (Naledi et al., 2011). The Millennium Development Goals lent a new urgency to a community-centric focus on health promotion, through strengthening CHW initiatives to reach specific targets (Chopra et al., 2009; Schneider et al., 2016).

In 2020, South Africa faces an ongoing struggle to reduce health inequalities and reach global targets in maternal, child, and population health (Pillay & Barron, 2018). Access to care remains deeply unequal, and high-quality health care that is both affordable and available is still out of reach for many (Besada et al., 2020). Consequently, CHW models of care may be well-positioned to address preventative health needs in a comprehensive, rigorous way, given the right conditions and support (Stansert Katzen et al., 2020). In the 2004 CHW National Policy Framework, and more recently in national strategies such as the re-engineering of primary health care (Pillay & Barron, 2011) and National Health Insurance (Smith et al., 2018), CHWs and community-oriented care have emerged as critical pieces of the South African health care landscape. Ward-based outreach teams (WBOTs) are the most recent attempt by national government to integrate CHWs into the existing public health care system and infrastructure (Mhlongo & Lutge, 2019; Schneider & Nxumalo, 2017; Schneider et al., 2018). However, CHW programming in South Africa remains highly fragmented, unregulated, and poorly coordinated (Nxumalo et al., 2013), with questions about quality, fidelity, and coverage underpinning efforts to scale and integrate these workers.

The Philani Mentor Mother model and the social franchise

A number of promising CHW programmes have emerged from this complex landscape, including the Philani Mentor Mother programme. Philani Maternal and

Child Health and Nutrition Project Trust, a South African NGO, first produced effectiveness evidence for its Mentor Mother model in 2014 (le Roux et al., 2014). The model was developed and first implemented in the peri-urban setting of Khayelitsha, outside Cape Town, to reduce child malnutrition and improve maternal wellbeing among vulnerable families through home visiting. The model draws on many of the principles represented in the work of David Olds and the Nurse-Family Partnership in the United States (Olds et al., 1997), as well as World Vision's 'positive deviant' mothers (Sternin et al., 1998). Positive deviants, while facing similar adversities as their peers, may adopt uncommon behaviours or coping responses that enable them to raise healthy children (Marsh et al., 2004). In drawing on the innate expertise and skills of these mothers, other mothers in situations of high adversity are theorised to be able to benefit and derive social support as well as health education and linkages to necessary resources.

Harnessing the value of this group of CHWs known as "Mentor Mothers" (MMs), Philani has grown to effectively meet vast maternal and child health needs in Khayelitsha. To date, Philani's model has been assessed through a long-term RCT (Rotheram Borus et al., 2011); it has shown positive effects on exclusive breastfeeding, infant birth weight, and antiretroviral adherence in the early follow-ups, as well as sustained impacts on child vocabulary at later follow-ups (Tomlinson et al., 2016).

Given the promise of the MM model on a localised scale, Philani developed an interest in translating the model to other settings where maternal and child health and nutrition is sub-optimal. However, this dissemination required a shift in approach, given Philani's status as a small NGO with a limited number of senior staff and financial resources. In 2016, Philani entered into a social franchise with One to One Children's Fund to initiate and adopt the MM model in Nyandeni, a rural part of the Eastern Cape

Province of South Africa. This franchise is known as the Enable Mentor Mothers Programme and is referred to as “Enable” throughout this dissertation.

Social franchising offers one pathway to expand and replicate evidence-based interventions more quickly in resource-limited settings. As a model, it purports to address two key issues in development: taking successful projects to scale and avoiding the continual reinvention of existing models. The overall aim of a social franchise is to share ideas and expand social impact for a broader population (Beyeler et al., 2013). Social franchises may draw on support from the originating organisation or model developer, or be structured around continued support from this organisation, but such franchises implement a model with new managers drawn from the new setting (Koehlmoos et al., 2009). As such, it is an attractive model for programme implementers seeking sustainability and local uptake, in tandem with scaling up evidence-based interventions. While this model promises to provide a strategic path to addressing complex issues by building on proven models and allowing for adaptation, few researchers have evaluated the mechanisms through which this model may be effective (Tougher et al., 2018), and overall assessments are mixed (Beyeler et al., 2013).

Nonetheless, a social franchise iteration of a model presents a distinct opportunity to examine a programme shown to be effective elsewhere, potentially defining a pathway for proceeding with a larger level scale-up if it can be successfully established. It is possible that, as with translating from effectiveness studies to dissemination, social franchising to a new setting and under a new management team may alter, or erase, certain core provisions of what makes a programme effective.

Rationale for the present study

Enable's establishment as a social franchise—a step towards scale for Philani's MM model—provides an important and timely opportunity to observe the process of programme implementation more closely. Specifically, it offers a chance to focus on the less-commonly researched processes described above: fidelity to training, client responses to the intervention, and contextual factors affecting implementation. While a social franchise model can be assessed through a rigorous RCT, in this dissertation, I use implementation science methods to explore these specific processes more comprehensively.

This research offers a granular perspective on the interpersonal aspects of implementation. By assessing the interactions between Enable's MMs and their clients, and interviewing them independently, this study contributes to an understanding of how client-MM engagement can affect relationships and potentially drive behaviour change to improve health outcomes. Relatedly, it also seeks to ground these perspectives in a broader context, considering the Enable Programme within the deeply rural context in which it operates. This focus is crucial for understanding why programmes may be effective, or not, and may provide a framing for other programmes seeking to implement maternal and child health interventions in rural communities.

As a model designed to improve health outcomes and reduce inequities in health access, the findings derived from this dissertation may hold important lessons for Enable's further scale-up, in South Africa and elsewhere.

Research questions

The aim of this study was to explore the processes underpinning the delivery of a community health worker programme in rural South Africa. Each research question

focuses on a diverse yet linked aspect of how programme implementation occurs, mapped clearly against the UK MRC framework (Figure 1 above, p. 10). These processes include the CHWs' fidelity to their training (implementation); client responses to and interactions with the intervention (mechanisms of impact); CHWs' experience of implementation in a given context; and clients' experience navigating formal health services in a given context (both linked to context). In line with these processes, this dissertation is focused around four research questions.

Research question 1: What happens as CHWs move from training to delivery, and do CHWs implement core training skills on communication and rapport-building in the context of the home visit?

Little is known about the processes that shape effective implementation of community health programmes in low-resource settings, and whether what actually happens during home visiting adheres to the training received. In response, I developed a checklist, the Home Visit Communication Skills Inventory (HCSI), to explore how Enable's MMs delivered the intervention to their clients (Laurenzi et al., 2019). I assessed transcripts of audio-recorded home visits for core communication skills from training. The HCSI, developed in line with other communication frameworks, organised skills by domains of active listening, active delivery, and active connecting. This question sets out to establish if audio-based checklists can be used to document and describe fidelity to a model in the absence of additional supervision or resources for programme monitoring.

Research question 2: How do clients of CHW programmes experience the delivery of the programme, and how do they engage with their CHWs?

Although CHW programmes were historically conceptualised as a way to meet the needs of the most vulnerable populations, these programmes have in recent years been viewed as convenient solutions to diffuse health tasks and reduce health system burdens more broadly (Schneider et al., 2016). These additional tasks may reduce the time that CHWs need with clients to be effective in building relationships and promoting key health practices. Furthermore, clients themselves have rarely been included in speaking to their own priorities or evaluating CHW programmes as recipients of these services. This component of the study seeks to incorporate perspectives from a subset of Enable's clients about their relationships with their MMs, and the ways in which they engage them.

Research question 3: How do CHWs navigate between their personal lives and their professional roles as they work in their own communities?

While task-shifting to CHWs has become an attractive solution to address shortages in human resources, community health workers often shoulder additional burdens as members of the same communities in which they work. These considerations can pose challenges to how they carry out their roles, yet are rarely considered. In this chapter, I explore how Enable's MMs navigate between the personal and professional crossroads and look to make recommendations to support CHWs on an individual and programmatic level.

Research question 4: How do pregnant women and new mothers navigate and respond to barriers in accessing formal health care and services for themselves and their infants?

Barriers to formal maternity care persist even in contexts where CHW interventions have been implemented. Less is known, however, about the diverse ways

that pregnant women and new mothers respond to, and navigate, these barriers. While Enable aims to improve clients' health education and facilitate referrals to care, it is also important to understand the experiences of clients outside the context of the programme, as not all essential care can be provided by MMs. This question provides an opportunity to more closely understand the contexts in which Enable's clients live. I document clients' responses to persistent barriers and consider ways in which the formal health system can work together with community-based programmes to improve quality of care to prioritise their health at a time of vulnerability.

This dissertation does not aim to conduct a full-scale process evaluation of the Enable Programme. However, specific to this dissertation, each of these domains helps frame my research questions and organise how larger questions of process, delivery, and acceptance, are considered.

Structure and layout of dissertation

This dissertation has been conducted in a thesis-by-publication format. This approach is accepted at Stellenbosch University and was valuable as it allowed each article to be conceptualised and interrogated individually and in detail. It also facilitated a degree of flexibility as my research plans, data collection and analysis progressed. This dissertation is organised in three main parts, further clarified in Table 1 below (p. 25). The publication status of each of the four findings chapters is also presented in this table.

Part A contains Chapters 1 and 2, presenting the background and theoretical framework, and methodology. In Chapter 1, I provide a rationale for the study, and situate my research questions more broadly in the scholarship about CHWs, intervention programmes and evaluations, and ideas about how successful scale-up can take place. I also introduce the framework that is used to organise the main findings of this study. In

Chapter 2, I briefly describe methods related to each individual objective. Because each findings chapter is a standalone article and contains its own methods, this chapter is relatively concise.

Part B contains Chapters 3-6, which describe the findings from this study. Chapters 3 and 4 focus on interpersonal aspects of implementation. Chapter 3, entitled *The Home Visit Communication Skills Inventory: Piloting a tool to measure community health worker fidelity to training in rural South Africa*, narrows in on what happens in the home visit setting by assessing transcripts of audio-recorded home visits through a novel communication checklist. Chapter 4, entitled *Instructive roles and supportive relationships: client perspectives of their engagement with community health workers in a rural South African home visiting programme*, explores how clients experience and interact with the Enable intervention, specifically through the contact point of their MM. It simultaneously asks about the dynamics that might facilitate and/or encourage behaviour change. Chapters 5 and 6 adopt a broader focus on the Enable Programme's context, and the communities and systems in which the intervention is embedded. Chapter 5, entitled *Balancing roles and blurring boundaries: Community health workers' experiences of navigating the crossroads between personal and professional life in rural South Africa*, explores how MMs navigate their roles as both community members and lay health workers. Chapter 6, *How do pregnant women and new mothers navigate and respond to challenges in accessing health care? Perspectives from rural South Africa*, moves outside the domain of the programme to explore the experiences of clients accessing formal health services and to document their responses to the barriers they face.

Part C presents Chapter 7. In this final chapter, I discuss how my findings across each chapter form part of a broader narrative on implementation of CHW programmes.

I close with recommendations for practice and research, and briefly share my conclusions.

Table 1: Layout of dissertation chapters and publication status

Part	Chapter, title	Publication status
A	Chapter 1: Background and literature review	
	Chapter 2: Methods	
B	Chapter 3: The Home Visit Communication Skills Inventory: Piloting a tool to measure community health worker fidelity to training in rural South Africa	Published in <i>Research in Nursing & Health</i> . Laurenzi, C. A., Gordon, S., Skeen, S., Coetzee, B. J., Bishop, J., Chademana, E., & Tomlinson, M. (2020). The home visit communication skills inventory: Piloting a tool to measure community health worker fidelity to training in rural South Africa. <i>Research in Nursing & Health</i> , 43(1), 122-133.
	Chapter 4: Instructive roles and supportive relationships: client perspectives of their engagement with community health workers in a rural South African home visiting programme	Under review at <i>International Journal for Equity in Health</i> .
	Chapter 5: Balancing roles and blurring boundaries: Community health workers' experiences of navigating the crossroads between personal and professional life in rural South Africa	Under review (received a revise and resubmit on 15 July 2020) at <i>Health and Social Care in the Community</i> . Revision submitted 24 July 2020.
	Chapter 6: How do pregnant women and new mothers navigate and respond to challenges in accessing health care? Perspectives from rural South Africa	Published in <i>Social Science & Medicine</i> . Laurenzi, C. A., Skeen, S., Coetzee, B. J., Gordon, S., Notholi, V., & Tomlinson, M. (2020). How do pregnant women and new mothers navigate and respond to challenges in accessing health care? Perspectives from rural South Africa. <i>Social Science & Medicine</i> , 258, 113100. https://doi.org/https://doi.org/10.1016/j.socscimed.2020.113100
C	Chapter 7: Discussion	

Chapter 2: Methodology

In this chapter, I introduce the methodology of the dissertation. I provide a brief overview of the study's design, research questions, and participants. Because Chapters 4 to 7 were conceptualised as standalone articles, more detailed methods are present in each of the chapters. I close with a set of reflections on conducting this work.

This study took place in the context of an ongoing collaboration between the Institute for Life Course Health Research (ILCHR) at Stellenbosch University and One to One Children's Fund, through which the ILCHR team provided monitoring, evaluation, and operational support.

Research design

This dissertation employed a mixed methods design, using predominantly qualitative data, to answer its four research questions. The study's research questions are repeated in the global table (Table 2) below. In addition, the data source used to answer the question, the article linked to each question, and the domain of process evaluation evaluated are listed, in order to link to the MRC Framework shared in Chapter 1 (p. 10). The three types of data collected (home visit audio recordings, client interviews, and MM interviews) formed the basis for separate articles, speaking to diverse but expressly chosen aspects of the programme's implementation.

Table 2: Global table of research questions and data

Research question	Data source	Article/Chapter title	Process evaluation focus
1. What happens as CHWs move from training to delivery, and do CHWs implement core training skills on communication and rapport-building in the context of the home visit?	Home visit audio recordings (n=84)	The home visit communication skills inventory: Piloting a tool to measure community health worker fidelity to training in rural South Africa	Fidelity (implementation)

2. How do clients of CHW programmes experience the delivery of the programme, and how do they engage with their CHWs?	Client interviews (n=26)	Instructive roles and supportive relationships: client perspectives of their engagement with community health workers in a rural South African home visiting programme	Participant responses to intervention (mechanisms of impact)
3. How do CHWs navigate between their personal lives and their professional roles as they work in their own communities?	Mentor Mother interviews (n=10)	Balancing roles and blurring boundaries: community health workers' experiences of navigating the crossroads between professional and personal life in rural South Africa	Contextual factors that affect implementation (context)
4. How do pregnant women and new mothers navigate and respond to barriers in accessing formal health care and services for themselves and their infants?	Client interviews (n=26)	How do pregnant women and new mothers navigate and respond to challenges in accessing health care? Perspectives from rural South Africa	Contextual factors that shape theories about how the intervention works (context)

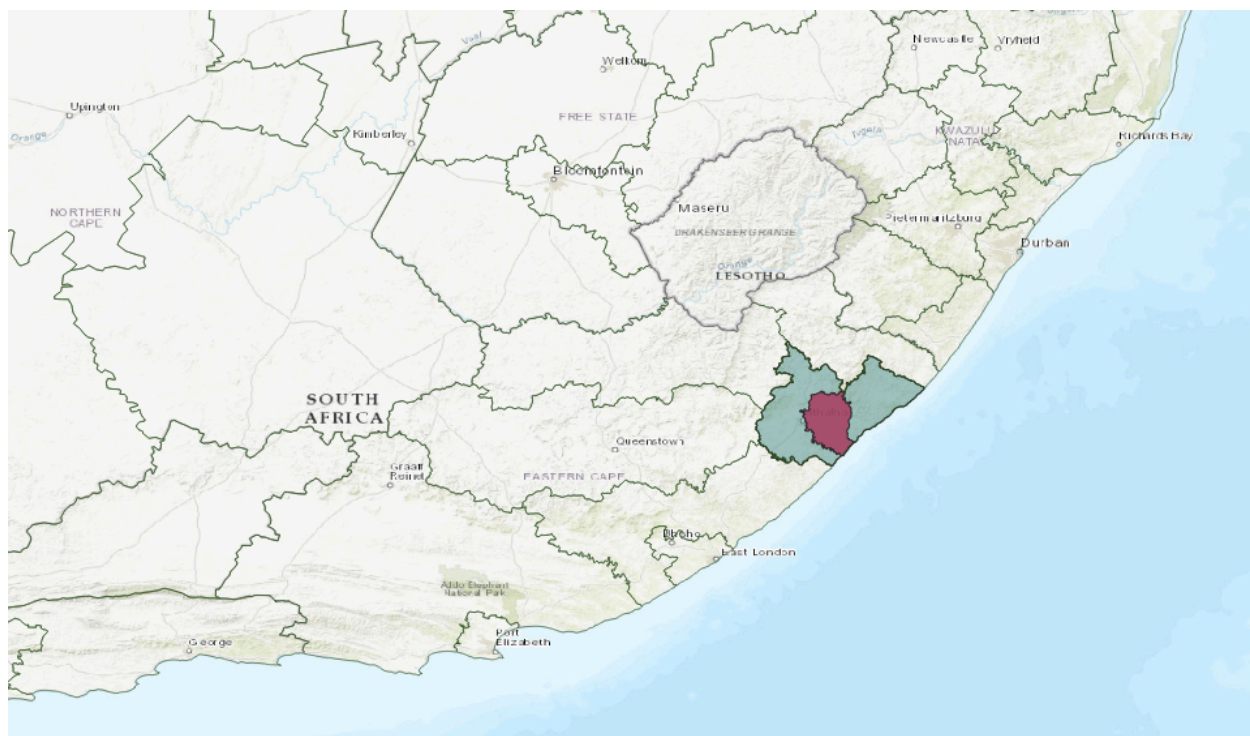
Setting and population

One to One Children's Fund, following an agreement with Philani, initiated Enable as a social franchise in 2016. Newly hired programme staff selected the Nyandeni Municipality, in the O.R. Tambo District of South Africa's Eastern Cape Province, as the project site. This selection was made based on its remoteness, its lack of existing health programming, and its poor maternal and child health indicators (Whiting, 2017). In Philani's model, potential MMs are identified by traditional or other community leaders, as well as through advertisements. After submitting curricula vitae, a subset of applicants is selected to participate in a six-week training with experienced trainers. The training focuses on health topics including but not limited to antenatal and postnatal care and nutrition, infant care and feeding, and HIV, as well as communication and teaching skills (Philani, 2016). The sessions combine didactic lessons with role plays, discussions, and written exercises. Trainees who pass the final written examination at the end of training are further evaluated on the basis of where they reside, and one MM per geographic area is selected. Beginning with support from a supervisor, MMs conduct

house-to-house visits on foot, enrolling pregnant women as well as undernourished children as clients. Pregnant clients are followed up throughout pregnancy as well as afterwards for up to 6 years, and MMs provide both standard and tailored care to each client depending on their specific needs. Philani pays MMs a modest monthly stipend for carrying out their roles. From the programme's inception, Enable followed these same procedures for recruitment, training, selection, and implementation, with guidance and support from Philani's senior management.

Enable was implemented in an extremely remote rural ward area in Nyandeni Municipality that had had limited experience with an NGO presence. Figure 2 shows Nyandeni Municipality (in purple) in respect to the O.R. Tambo District (in teal) and the rest of South Africa.

Figure 2: Map of Nyandeni Municipality and the O.R. Tambo District



The O.R. Tambo District is one of South Africa's poorest districts and covers an area of 12,096 km² (Statistics South Africa, 2011). Nyandeni's health and living indicators, like those of O.R. Tambo more broadly, are well below national averages and depict a challenging landscape for maternal and child health access and outcomes in particular (Massyn et al., 2017). The chapters that follow, each conceptualised as a standalone article, highlight specific aspects of the setting.

Overview of data collection and analysis processes

In this overview section, each research question is paired with the participants and data source used to answer each research question. Each chapter contains its own detailed description of the data collection processes for the associated data.

Research question 1: What happens as CHWs move from training to delivery, and do CHWs implement core training skills on communication and rapport-building in the context of the home visit?

To answer this question, I collected, with consent, n=84 audio recordings of routine home visit sessions that MMs conducted with their maternal clients. These audio recordings were translated and transcribed by a transcription team in Cape Town, and the resulting transcripts were analysed using the Home Visit Communication Skills Inventory (HCSI), which I devised by drawing across both the evidence base and programme-specific training areas. While qualitative data formed the basis for answering this question, the presence or absence of key practices was collated and quantified across individual MMs' visits and across key domains, enabling a mixed-methods approach to understanding these findings. ATLAS.ti qualitative software was used to organise and code data, in tandem with Microsoft Excel to help organise findings. A fully detailed

account of the methods for this research question can be found in Chapter 3, beginning on p. 37.

Research question 2: How do clients of CHW programmes experience the delivery of the programme, and how do they engage with their CHWs?

This question relied on semi-structured interviews with a subset of clients (n=26) as its source of data. All interviews were conducted by Vuyolwethu Notholi, an experienced research assistant and interviewer who has worked with the ILCHR team on various project for over a decade. All interviews were conducted in isiXhosa and transcribed and translated in Cape Town by a transcription team. ATLAS.ti qualitative software was used to organise and code data. A fully detailed account of the methods for this research question can be found in Chapter 4, beginning on p. 63.

Research question 3: How do CHWs navigate between their personal lives and their professional roles as they work in their own communities?

This question relied on semi-structured interviews with MMs (n=10) as its source of data. The interviews and transcriptions were conducted as above. ATLAS.ti qualitative software was used to organise and code data. A fully detailed account of the methods for this research question can be found in Chapter 5, beginning on p. 87.

Research question 4: How do pregnant women and new mothers navigate and respond to barriers in accessing formal health care and services for themselves and their infants?

This question relied on semi-structured interviews with clients as its data source (n=26, the same interviews used to answer my second question). Its focus was slightly different, and as such, its thematic coding focused on data describing health access,

health-seeking, and responses to challenges. A fully detailed account of the methods for this research question can be found in Chapter 6, beginning on p. 111.

Ethical considerations

Approval and permission

Stellenbosch University's Health Research Ethics Committee granted ethical approval for this study (N16/05/062).

Considerations for ethical community-based research

This study's methodology was informed by three overarching principles for ethical community-based research: transparency, non-interference, and knowledge dissemination.

All interviews were conducted in participants' home language, isiXhosa, to ensure that participants were able to engage fully with the questions, and share responses, in the language in which they were comfortable communicating. Furthermore, as will be explained in the sections that follow, an informed consent process (again conducted in isiXhosa), was followed each time individual participant data was collected.

In planning and arranging data collection, I strove to pose minimal interference with the Enable Programme's usual operations. Home visits and interviews were scheduled through a transparent channel of communication with Enable Programme supervisors. Supervisors also helped coordinate a special session with MMs to inform them about data collection, and particularly, about the recording of a random subset of their home visit sessions with clients. Efforts were made to allay any uncertainties or anxieties associated with these recordings of MMs' visits, and to ensure they understood

that they were not being closely scrutinised. While an independent data collector accompanied the MM on her selected day(s) to administer informed consent and manage the start and stop of the audio recording, we designed the process for this individual to be as brief as possible, not interfering or observing the actual visit herself. Specifically, while administering informed consent, research assistants were trained to: 1) communicate participants' rights to refuse explicitly, 2) carefully explain the difference between the typical home visit and this once-off audio recording, and 3) describe to the client that this recording would only be used by university researchers for learning lessons about how home visiting programmes operate. These principles were prioritised in order to mitigate any risk of misunderstanding or concern.

At the end of data collection and analysis, I returned to Nyandeni and held a dissemination day meeting with all MMs and staff in July 2019, which included a number of new staff members who had joined Enable subsequent to my research. I presented a general set of de-identified findings using a slideshow and portable projector, giving opportunities to ask questions and discuss themes. Following the presentation, the supervisors and I set aside time to engage the staff in discussions about ongoing challenges and needs.

Salient findings were further shared with Enable's senior management through routine reports and the final Phase 1 project report submitted in mid-2019. In our team's proposal to work with Enable for the second phase of their funding, we were able to integrate key findings and challenges raised during the research into ideas for collaborating in this next phase—thus strengthening the quality of Enable's implementation as it continued to expand into new neighbouring areas.

Reflections

In this short chapter, I include some reflections to contextualise my role in the research and data collection in particular. My first visit to South Africa was as an intern for the Philani Nutrition Centres Trust in Khayelitsha from June to August 2012, as an undergraduate studying Global Health and Health Policy as well as Politics at Princeton University. Over the course of the past eight years, my professional research and policy interests have both expanded and become clearer, however my dissertation is still very closely linked to this initial exposure to Philani's home-based maternal and child health care programme.

The following year, in July 2013, I moved to Zithulele, in the rural Eastern Cape, to begin a one-year fellowship working with Philani and Zithulele Hospital. In co-managing a cohort study following infants for the first year of life, I planned daily logistics, oversaw a team of female isiXhosa data collectors, and conducted data quality control. This experience gave me both foundational research skills but also a closer understanding of Xhosa culture and the realities of living in a remote, rural area. I learned much about the challenges that mothers and their infants faced in accessing health care, absorbing the details of their lives through many hours of poring over questionnaire responses, and I also spent ample time accompanying and conversing with data collectors on field visits in participants' homes and occasionally at government-funded public health clinics.

This prior experience—both with the Philani home visiting model, and in a rural area that resembles Nyandeni and is 19 kilometres from it as the crow flies—was formative. It was also essential to the insight that I was able to bring to this research process, having come from a privileged and very different upbringing. Over the course of this doctorate, I made 11 visits over two and a half years, ranging from five to ten days

each, to spend time at Mankosi and in the surrounding areas with the programme. These visits were in my capacity as a project manager as well as for my research, and I attended monthly meetings, co-led trainings, and reviewed case files over these visits in addition to managing the research. Throughout this engagement with the programme, I gained a better understanding of some of the dynamics of implementing community-based programmes in this area.

Vuyolwethu Notholi (Vuyo) conducted all interviews with the informants in this thesis, and I decided not to accompany her during this process. The language barrier was one reason for this decision, and as a non-Xhosa person, I did not want to feel as if I was present without being able to contribute or engage on a deeper level. While senior managers and even funders do accompany MMs from time to time, I did not want any information to be compromised, and did not feel it was useful or necessary for me to accompany Vuyo from a supervisory standpoint. Vuyo, with approximately a decade of experience in research, had been born and raised in a different part of the Eastern Cape, but was able to easily bridge worlds between researcher and participant. As such, I was confident in her ability to thoughtfully and meaningfully engage with participants, and we had regular discussions about how to approach certain questions, translate certain concepts, and manage unforeseen challenges in participant rapport.

While these considerations were more pressing for home visit audio recordings and client interviews, I could have more easily sat in on interviews with MMs. However, I again felt that having some distance could allow MMs to open up more easily. Having worked closely with this first cohort of MMs over the course of the project, I wanted them to feel comfortable speaking with Vuyo without any pressure and in their own language. While the MMs were all familiar with Vuyo, she was very much separate from

their management and oversight, whereas I reviewed case files as part of my supporting monitoring & evaluation role with project.

These decisions were also made with explicit understanding of my role as a white, highly-educated American woman. I wanted to be aware, from the start of this work, of how my background and identity might affect the way I approached and framed my research. I also wanted to ensure that I engaged in respectful and mindful research practices along all phases of this doctorate. I first realised in Zithulele that the research participants with whom I interacted did not readily distinguish between me and other white South Africans, and I was reminded of this fact again in my interactions with Enable's MMs. While this may have granted me a sense of being seen as more of an 'insider' than being seen as a foreigner, in many ways, this lack of distinction served as a reminder of the vast inequalities by race, culture, language, and socioeconomic status that are present in South Africa today.

The prior experiences I describe above enabled me to become more familiar with aspects of South African culture specific to the Eastern Cape and area in which I was working. I feel that this extended time in the area lent me a more nuanced perspective that I was able to bring to this work, which was an advantage. However, it is clear that my upbringing in a mostly-white affluent suburb in New Jersey limited the depth of my connection with and understanding of this context. The inherited systemic and intergenerational disenfranchisement of black South Africans has been perpetuated through inequitable research partnerships and programming, among many other ways. I acknowledged this power dynamic and also sought to mitigate further harm throughout this process.

As a researcher entering the field with these privileges, I wanted to be sure that my presence in these interviews would not be assumed; that my research questions or

intent would not be exploitative or seen as such; and that my perceptions or analyses of the data could be done both systematically but also with a sense of cultural understanding. I read research outputs from similar community-based health research consistently throughout the period of my doctorate, and regularly reflected on my time in Mankosi through personal writing and many conversations. My continued communication with Vuyo, as well as the members of the transcription and translation team, were essential in this regard. By working closely with Vuyo, she and I were able to ensure that this research was mindfully conducted, and I am confident that participants did not feel unduly pressurised to participate. Similarly, I devoted time to building and maintaining a positive working relationship with Vuyo and the rest of the team, but also sought to acknowledge and lessen the power dynamics and balance of responsibilities between and among us to the best of my ability.

Lastly, I conducted two first-person interviews with English-speaking staff; the first programme manager who had initiated the programme, and a doctor from the Netherlands who had come to work at Canzibe Hospital and later left to volunteer with Enable for one year, conducting home visits with clients with special needs. These interviews, which I have utilised as personal communications, provided a strong sense of context and important details about early-stage implementation efforts, however, they were not used as raw data for this dissertation. Furthermore, Vuyo conducted four additional interviews with Enable's field supervisors that were ultimately not used for this dissertation. While I am confident that the methodological and reflexive decisions that I made as part of undertaking this research contributed to the generation of overall high-quality data, I discuss potential limitations at the end of Chapter 7, beginning on p. 164.

Chapter 3: The Home Visit Communication Skills Inventory: Piloting a tool to measure community health worker fidelity to training in rural South Africa

Introducing Article 1

This chapter contains the first of four articles around which this dissertation is based. In this paper, I explored MMs' fidelity to their training by collecting audio recordings of home visit settings. These recordings, which were transcribed and translated into English, were analysed using a newly developed, 21-item checklist, the HCSI, which focused specifically on communication skills employed by MMs in their visits. I found that, while in general, MMs scored highly in domains of "active listening" and "active delivery," there were more variable findings across the domain of "active connecting" which highlighted relationship-building skills.

This article has been published in *Research in Nursing & Health*. It is reproduced as an in-text chapter in this dissertation, in the same style as it was submitted for publication. It is available in its PDF article format in Appendix A (p. 221), and can also be found at the following reference:

Laurenzi, C. A., Gordon, S., Skeen, S., Coetzee, B. J., Bishop, J., Chademana, E., & Tomlinson, M. (2019). The home visit communication skills inventory: Piloting a tool to measure community health worker fidelity to training in rural South Africa. *Research In Nursing & Health*, 43(1), 122-133.

Abstract

Community-based home visiting programs using CHWs have become popular modes of delivering health care services, especially in settings where health workers are overburdened and resources are limited. Yet, little is known about the processes that shape effective implementation in low-resource settings, and whether these processes adhere to home visitors' training. This study used the newly-developed HCSI to explore the delivery of a CHW programme in rural South Africa. Routine home visits from CHWs to their maternal care clients were audio-recorded with consent, and later transcribed and translated into English. The HCSI, devised and piloted using existing frameworks and program-specific training components, consisted of 21 items covering domains related to active listening, active delivery, and active connecting, and was used to score English transcripts of the home visits. The HCSI was used to generate general frequencies and aggregate scores for each CHW. Eighty-four home visits by 14 CHWs showed a diverse application of communication skills. Active listening and active delivery were common, with fewer instances of active connecting observed. Practices disaggregated by CHW showcased varying strengths per individual. In reviewing visit characteristics, longer average visit duration was significantly correlated with the presence of multiple types of active connecting skills. While technical skills were widely observed, fewer CHWs engaged in more complex "connecting" skills. The HCSI is a feasible, low-cost, and practical way to describe home visit fidelity among CHWs. Audio-based checklists can be used to describe fidelity to a model in the absence of additional supervisory resources.

Introduction

Community-based home visiting programmes are key modes of delivering health care services, especially in settings where facility-based health workers are overburdened and resources are limited (Tulenko et al., 2013). Much of the evidence promoting home visiting programmes has come from studies focused on assessing their impact (Bhutta et al., 2013; Christopher et al., 2011; Haines et al., 2007; Hill et al., 2014; Lewin et al., 2010). While for the most part impacts have been positive, there have been varied results, in part because the ways in which these programmes are implemented can vary tremendously. The evidence supporting home visiting programmes has often failed to translate to practical, “real world” effectiveness, especially when these programmes are expanded and replicated in new settings. Barriers to this knowledge translation include the lack of human and financial resources to adequately scale programmes (Haines et al., 2007), inattention to contextual factors that may limit a programme’s acceptability to its beneficiaries (Blacklock et al., 2016) and fidelity to the intended intervention.

Fidelity is a crucial, yet often overlooked, part of implementing home visiting programmes (Kim et al., 2015). Fidelity to an intervention relates to both content (is key content delivered as intended?) and structure of delivery (are core practices being enacted as intended?) (Dunst et al., 2013). The first category presents practitioners and researchers with more clear-cut tools, enabling the measurement of dosage and content delivered. However, less tangible processes, such as implementer competence, are more difficult to engage, identify, and measure (Tomlinson et al., 2018). Implementer competence relates to communication, skills, and abilities that can affect the intended delivery of an intervention (Breitenstein et al., 2010). These factors are likely to be just as important in determining a programme’s success as the number of visits completed, or the degree of adherence to a manual (Korfmacher et al., 2007; Schodt et al., 2015).

Nonetheless, measures of dosage and content have up to now proven to be easier, and less expensive, than more thoroughly examining soft implementer skills.

A number of contextual factors highlight the need for more investment in implementer skills, especially in low-resource settings. Evidence from home visiting programmes indicates that simply relaying content or delivering instructions is not sufficient to make interventions effective (Brookes et al., 2006). Implementer competencies such as manner of engagement, body language, and communicative style can determine whether or not a client wants to begin or continue a clinical relationship (Breitenstein et al., 2010). Often, CHWs from low-resource settings require more training in these skills. While they may have local buy-in and be culturally similar to their clients (Kilpatrick et al., 2009), they also tend to be lay workers with limited employment, education, and pre-service training experience (Glenton et al., 2013; Kemp & Henderson, 2012). Supportive supervision, which can mitigate these shortcomings, is often not possible in programmes that are under-resourced and geographically dispersed. Thus, for CHWs to deliver interventions with fidelity, they ideally require a core set of competencies and opportunities to build and develop individual skills for their role, as well as an organisational environment conducive to nurturing these skills. Limitations in funding, supervision, and geographical and social context can act as barriers to quality in implementation.

It is important to consider means to extract key implementer skills and find simple, yet valuable ways to measure these skills and how they may affect the delivery of an intervention. Motivational interviewing and communication analysis literature, which includes analysis of patient-clinician interactions (Kilian et al., 2015; Roter & Hall, 1992), can provide a template for measuring softer implementer skills, such as communication style and interpersonal competencies. The available evidence

emphasises creating solidarity or establishing an emotional bond; using different types of questions or speech prompts to gather information; providing information through facilitation, instruction, or direction; responding to information given as well as to feelings or concerns; and a focus on reciprocity or cooperation in making decisions about health behaviours (King & Hoppe, 2013; Roter, 2000b). To capture these factors, checklists can present more streamlined ways of translating findings to operational contexts; they have also been used in process research as well as health care settings to assess quality, standardise delivery, and observe fidelity (Dorsey et al., 2018). However, few checklists are present in community-based care settings, especially as they relate to implementer skills.

In this study, we considered the most effective and practical way to capture implementer (CHW) competence related to a specific set of communication strategies. Communication strategies are one skill set that training may cover, yet little research has been done on how well this training translates into a home visiting setting (Roter & Hall, 1992). We piloted a communication checklist, which we entitled the HCSI, to explore the delivery of a CHW programme in rural South Africa. This descriptive study aimed to capture communication skills in a home visit setting as part of a larger study about CHW fidelity to a home-based maternal and child health intervention. What happens as CHWs move from training to delivery, and do we observe CHWs implementing core strategies from training on communication and rapport-building in the context of the home visit?

The model and context

The Enable Programme is a rurally-based home visiting intervention, established as the first “social franchise” of the Philani MM model. “Social franchising” involves similar concepts to commercial franchising, where a model is taken to a new setting

under new management, but aims to accomplish social ends, instead of seeking profit. In the MM model, local mothers are identified through informal networks such as community leaders or village/neighborhood meetings, then selected and trained to deliver a home visiting intervention (Le Roux et al., 2015). The programme specifically looks for “positive deviants”—mothers who have been able to rise above adversity to raise healthy children—to provide support and education to their peers (Marsh et al., 2004). Master trainers conduct a six-week training course for MMs, which includes didactic lessons on health information, practical skills about establishing relationships and connecting to clients, and role play and problem-solving practice sessions. Following this training, trainees complete a final examination. Performance during training and on the examination, as well as logistical considerations such as where each woman resides, determine which of the trainees are ultimately selected as MMs. The selected MMs recruit pregnant mothers from their own village catchment areas and conduct routine home visits to educate and support clients through pregnancy, delivery, and their infants’ first years of life. The programme’s key focus areas include maternal and infant wellbeing, child nutrition, immunisation, HIV/AIDS prevention and treatment, and access to social and health services. In addition to supporting pregnant and recently-delivered women, they also identify and visit undernourished children and clients with chronic conditions requiring home-based care.

Methods

Stellenbosch University’s Health Research Ethics Committee granted ethical approval to collect home visit data (N16/05/062).

Setting

The Enable Programme is based in the Nyandeni Municipality, in the O.R. Tambo district of South Africa's Eastern Cape Province. Preparations for the Enable social franchise began in early 2016. Training of potential MMs took place in May and June, and the MMs selected for employment began recruiting clients in July 2016. In addition to 14 MMs each operating in their own area, the original supervision team consisted of two supervisors (one with a clinical background and the other with operational roles) and one programme coordinator.

Nyandeni was selected for its poor health outcomes and access. Many of the critical health considerations facing South Africa's urban population, for which the Philani MM model was originally developed, are intensified in deeply rural settings like Nyandeni, where infrastructure is poor, options for transport to health centers are limited, and economic and employment opportunities are scarce (Massyn et al., 2017). As such, the social franchise approach and the translation of a model from one setting to another, presents an opportunity to consider fidelity in implementation and process.

Data collection procedure

This study used audio recordings of routine home visits to pregnant and recently-delivered clients of the Enable Programme. The data for this study were collected during a sample of routine home visits conducted by Enable MMs during visits with pregnant clients and new mothers and their infants. An independent isiXhosa-speaking research assistant accompanied each MM on a randomly selected day to all of her planned perinatal and infant visits, in order to obtain consent to audio-record the visit. No supervisors were present for these specific visits. We employed an independent research assistant to reduce risk of bias or of jeopardising the client-MM relationship, separating

the MMs from the data collection process as much as possible. MMs were notified 1-2 days prior that they would be accompanied. Before the routine visit began, the research assistant sat one-on-one with the client to review an informed consent form that contained simple language recommended by the ethics review board. Our method of translation included having all consent forms translated into isiXhosa by a research team member and quality-checked by a senior team member before use in the field. During and after review, the research assistant gave the client the chance to ask questions or to refuse to participate. If the client consented, the research assistant would start a new recording on a handheld audio recorder and exit the household, and the MM would enter.

Recordings began in January 2017, and were staggered by MM, with some MMs revisited to capture additional recordings, until February 2018. Additional recordings were sought to ensure a roughly equal number of visits for each MM. Informed consent forms were signed by all participants; audio recordings were downloaded and removed from the recorder on the same day as collection and kept in a secure location. Two isiXhosa-speaking transcribers were responsible for simultaneous transcription and translation from isiXhosa to English; approximately 25% of transcripts were reviewed by a senior isiXhosa-speaking team member for quality control purposes. All transcripts were anonymised using a participant identifier.

Developing the HCSI

In order to analyse key themes across transcripts of these audio-recorded home visits, we developed a checklist, the HCSI. We decided to use a checklist to capture the presence of key skills, in lieu of coding each phrase in the transcripts. The HCSI was developed using a combination of reported best practices from similar research,

programme-specific guidelines, and iterative additions. First, existing frameworks and measures from client-provider communication research were surveyed through literature searches including key words such as “patient-provider communication,” “client-provider-communication,” and “physician-client communication” (Abdel-Tawab & Roter, 2002; King & Hoppe, 2013; Roter, 2000b; Roter & Hall, 1992; Watermeyer & Penn, 2009). Related work evaluating home visit programme quality was also reviewed (Peterson et al., 2007; Roggman et al., 2016). Further literature was identified from these initial searches.

Secondly, in-depth notes were made from the Philani training manual’s module on communication, which teaches specific skills for communication and broader strategies for relationship-building within the context of the home visit (Philani, 2016). Six key questions about MM skills and behaviours during the visit were formulated, based on the core components of the training chapter. These questions guided the design of a draft checklist, synthesising the reviewed communication skills and adapting “best practice” frameworks to reflect specific features of the training. CL devised an initial checklist of 17 items, which was checked by SS and MT. During a pilot stage, approximately 20 transcripts were read and coded using this draft checklist, after which minor iterative changes were made to reflect the communication skills observed, resulting in the final HCSI, comprising 21 items (Table 3). Changes included the addition of two new categories, and the combination/division of existing categories.

Table 3: Home Visit Communication Skills Inventory (HCSI)

Domain	Communication strategies, guided by key questions
<i>Active listening</i>	Does the Mentor Mother employ each of the following active listening skills?
	Ask for clarification*
	Gather information+

	Reflect content/information given*
	Reflect feelings/concerns+
	Does the MM encourage dialogue by asking open questions, and engaging “tell me more” techniques or rhetorical devices?
	Asking open questions consistently (at least 3 examples)+
	"Tell me more" techniques*
<i>Active delivery</i>	Does the MM share relevant information that addresses the client’s situation, and/or reference prior visits to build on knowledge?
	Relevant new information (at least 3 examples)*
	Information retention (checking on information retained from a prior visit)+
	Visit continuity (regarding knowledge, health education imparted previously)°
	Does the MM ensure that the client understands her, and understands the choices she has to make?
	Ensuring comprehension+
	Soliciting questions*
	Using questions to probe understanding*
	Does the MM counsel the client in a way that suggests, rather than dictates or directs—meaning that the client has room to make her own health decisions?
	Clear "suggest" statements present, more than directives*
<i>Active connecting</i>	Does the MM show a range of diverse examples of connecting to the client?
	Empathy and/or understanding*
	Recognise, praise, or affirm*
	Non-judgmental attitude*
	Articulating confidentiality*
	Articulating trust in the relationship+
	Sharing similar experiences/observations°
	Other rapport-building evident+
	Visit continuity (regarding connecting again)°

Items drawn from three main sources, with some concepts rephrased for clarity and applicability:

*Philani Training Manual, 2016

+Roter Interaction Analysis System framework

°Iterative additions from home visit transcripts

Checklist scoring and analysis

Transcripts were organised in ATLAS.ti software, where codes were applied that matched the 21 HCSI items. A primary coder (CL) reviewed each transcript against the HCSI items, and coded a given phrase or exchange as reflecting this communication skill. After the transcript was reviewed twice by CL, the strategies coded were entered into a database using a 1 (present) or 0 (absent). A secondary coder (SG) trained on the HCSI coded 10% of transcripts and discussed scores with CL for reliability. In cases of disagreement, both coders met to discuss and resolve discrepancies; however, overall, there were very few instances where coders disagreed on the presence of an element (15/200 disagreements, 7.5%).

Analysis was conducted across two levels: first, general frequencies of observed communication strategies were recorded across all MMs. These frequencies were organised individually, and also into three domains: active listening, active delivery, and active connecting. These domains were devised as a way to group like skills thematically: listening, delivery, and connecting were chosen as three overall strategies that encompassed key skills for MM-client engagement, and that necessitated MMs taking an active role in driving the interaction. Active listening is commonly understood as having skills to concentrate, comprehend, and adequately respond to an individual over the course of a conversation or counseling session. Active delivery was conceptualised as a further step beyond this skill: selecting a response to the client's individual situation or needs, and following through on the information shared with that client to facilitate understanding, retention, and confidence on the part of the client. Active connecting, as a third overarching domain, was seen as additional skills related to fostering a relationship with the client and utilising strategies to build rapport in diverse ways.

Second, strategies were disaggregated by MM to observe variation among MMs and by domain. For each MM at each visit, items within each domain were summed (how many strategies observed of the total available), and an average of these scores was taken. These averages were then converted to proportions.

Results

Descriptive information

Home visit recordings. Table 4 (p. 49) shows a summary of descriptive information. In total, 84 home visits were recorded, transcribed and coded. While each of these 84 transcripts reflected separate home visit sessions, five clients were recorded twice (n=79 clients). The majority of clients were pregnant. Visit duration ranged from a quick check-in visit of three and a half minutes to a 34-minute session; the recorded visits averaged just over 16 minutes.

MMs. All 14 MMs were accompanied for a subsample of their visits with different clients to be recorded. On average, six visits per MM were recorded. In order to obtain a substantive number of audio recordings across all MMs, each MM was accompanied on either one or two full days to all of their daily visits.

Clients. Clients (n=79) were a mix of first-time mothers and experienced mothers; just over a third of clients sampled were expecting or had delivered their first child (35.7%), while seven clients (8.3%) already had four or more children before entering the programme. Eight clients (9.5%) were 18 years or under at the time of recruitment into the programme. While duration of relationship between MM and client ranged from one prior visit to 34 visits, the average number of visits prior to our recording session was 11.

Table 4: Descriptive information about the home visit recordings

Session information	N	Mean (M), standard deviation (SD), range
Audio-recorded home visits sessions coded	N = 84	
Home visits during client pregnancy	N = 53	
Home visits after client delivery (with child)	N = 31	
Length of visits (mm:ss)		M=16:13
		SD=7:15
		Range=3:30-33:54
Client information	N = 79	
Age of clients		M=25.72
		SD=6.23
		Range=15-41
Clients who are first-time mothers	N = 30	
Number of previous children, mean		M=1.42
		SD=1.57
		Range=0-7
MM information	N = 14	
Recorded visits per MM		M=6
		SD=1.52
		Range=3-8

Observed practices

The communication practices observed in home visit sessions are reflected using illustrative examples, as well as frequencies of HCSI observations by cohort and by individual MM, shown in Figure 3 (p. 51).

Active listening. Across recordings, most visits showed evidence of gathering information, and asking open questions (e.g., inquiring about feeding practices and follow-up dates), as well as probing clients to give more context about clinic visits or ongoing health issues. Most visits also gave evidence of the MM reflecting the

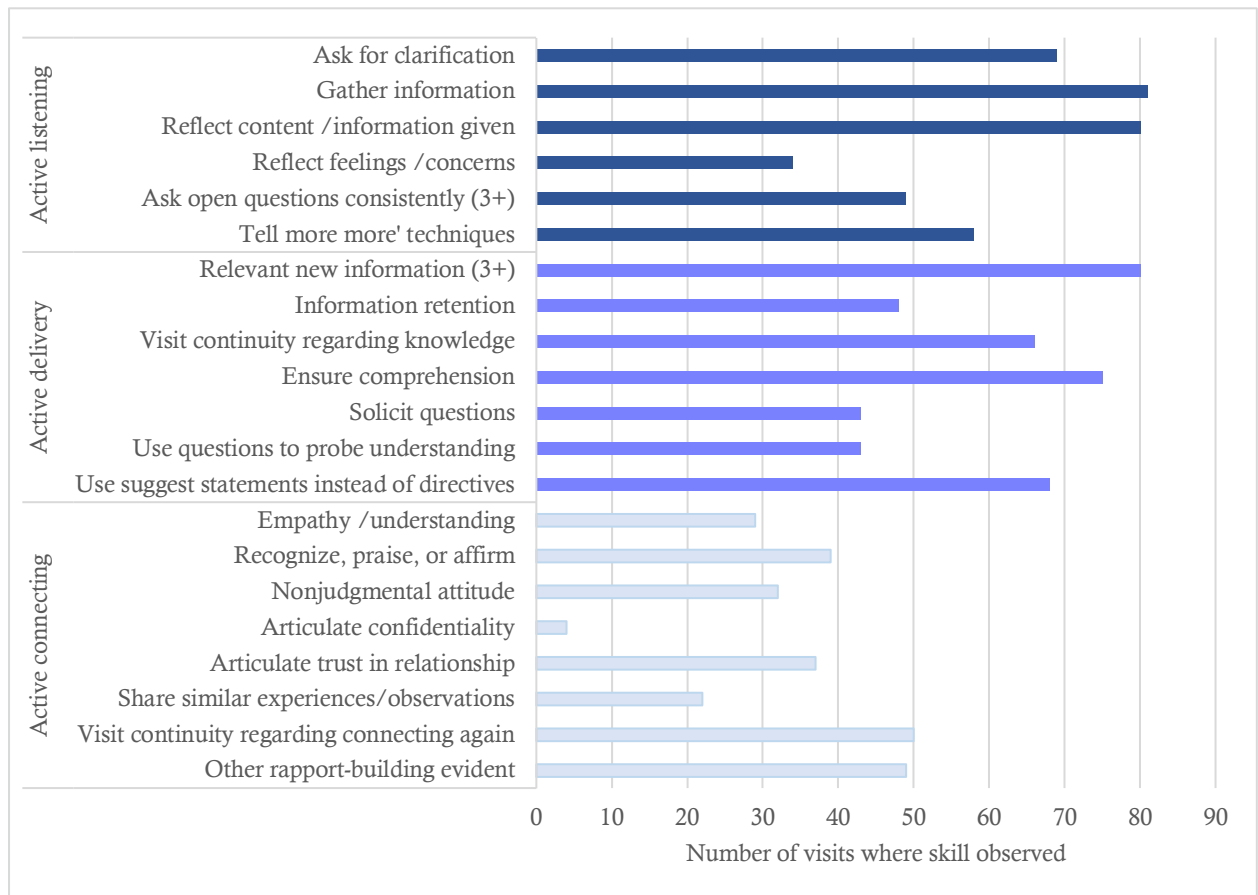
information or content she was given. These instances included reflecting information given verbally, information gathered from observing the child, and information gathered from reviewing health records such as the mother's maternity card or the infant's Road to Health Card (e.g., "Since it's written here on your card, it shows that you are HIV-negative").

The practice of asking for clarification was also present in over 80% of visits, for example, the MM asking, and 'tell me more' techniques, which might constitute a MM prompting, "Mmhmm...", or "What else?" were also observed across nearly 70% of visits. While reflecting content and information was common, reflecting feelings and/or concerns of the client was less common.

Active delivery. Nearly all visits showed at least three instances of the MM delivering information relevant to the client about her own health or pregnancy, as well as anticipatory advice for her baby's health. Ensuring comprehension and using suggestive (rather than directive) language were also common practices, present in over 80% of visits. Often MMs would conclude with "You see?" or "Do you understand?", but sometimes they used demonstrations or visual aids to ensure comprehension, such as the child's growth chart attached to the case file:

MM: [She] was on 3.4 kg, now on 3.7 kg, you see on this chart since there are these black lines, then there are these ones below, the baby's weight needs to be here (pointing), inside, if it is here, that means the baby's weight doesn't correspond with her age, maybe she had...flu or stomachache or whatever. So yours is inside this thing, she is on this thing (pointing) here.

Figure 3: Frequencies of communication strategies observed in HCSI (n=84 visits), domains coded by colour



Suggestive statements used key words such as *emphasise*, *suggest*, *encourage*, or other words conveying importance, without clearly instructing or directing the client: “because us, as Mentor Mothers, we do not encourage [baby cereal].” At times, these phrases were also used to give the client guidance about how to broach the topic with their partner, such as insisting on using condoms during sex:

The condom protects you and protects the baby...so now you need to show that you will be the caring parent, you will be the responsible parent from now, if you say something goes this way, say it to your partner that “it is like this,” also by the time you [are] breastfeeding, even though we are not there yet, [a] condom needs to be used.

A majority of visits also showed the MM following up on a health problem or behaviour discussed in prior visits, ensuring a sense of continuity in health education.

Over half of visits included checking on information retention from prior visits, soliciting questions and using questions to probe understanding, such as: “Do you still remember your date to go for a checkup at [the hospital]?” When MMs solicited questions, they would often finish explaining a health issue by saying, “Is there anything you don’t understand that you want to ask?” Using questions to probe understanding encompassed more deliberate examples, or using a client’s words to invite more explanation, such as, “why [are] you saying [your] baby doesn’t get full with breast milk?”

Active connecting. Discussing visit continuity regarding visiting again was the most commonly observed active connecting skill (59.5%). Examples of visit continuity included general statements, such as, “I’m going to visit you often, visiting you often as you are about to give birth, weekly, chatting and advising each other about constructive things.” They also included more specific scheduling by day or date, or conveying a sense of MM availability: “When there is something that you don’t understand, you just call me, I am easy to reach. You would ask what is happening, then I would tell you what to do.” A high proportion of visits demonstrated MMs employing similar rapport-building (connecting) techniques. Sharing similar experiences was less commonly observed, but used to establish rapport as well, such as a MM instructing her client to communicate with her after a clinic visit, “Yes, because—there is that thing of going to [the clinic] and not receiving immunisations.”

Nearly half of the visits (46.4%) showed evidence of the MM recognising, praising, or affirming the client. Often these phrases included a compliment about the baby, but sometimes comprised other affirmations: “You are doing an important thing,

sis, it is important to test and to know your status.” Articulating trust in the relationship was also present in nearly half of sessions, in which the MM might indicate a shared commitment: “as we come here often, we want to raise this child together.” Discussing trust also encompassed requests for openness by the MM:

A Mentor Mother then, as I’m visiting here, is a person to look after you and also when there is something that you don’t understand, you must ask and tell [me] that I have this thing, this problem, I have this thing that I don’t understand and ask. You are allowed to ask anything to a Mentor Mother without hiding anything.

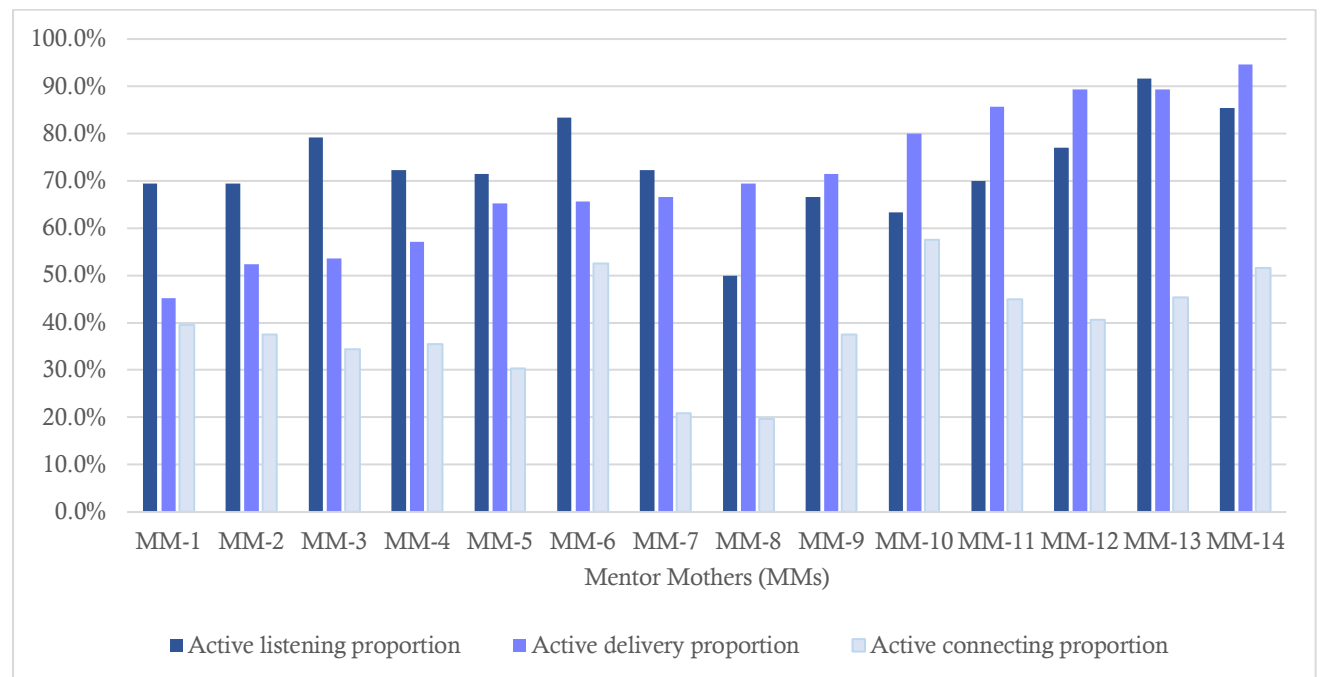
Fewer MMs were observed clearly articulating confidentiality by explicitly stating that they would not share the information covered in the sessions. One of the few examples included the following reassurance: “Every problem that you have... I don’t share it with anyone, I don’t go around talking about it, I don’t share it anywhere, even at home.” Empathy and understanding, and nonjudgmental statements, were also less commonly employed. In a nonjudgmental statement, the MM might convey information with a certain sensitivity: “The reason to check this virus is for in case it happens, I am not saying [it] is, if it can happen, that there is to try and protect the baby on time.”

Observed practices, by MM

The observed practices disaggregated by MM are shown in Figure 4 (p. 54), and indicate significant variations by MM. All MMs had higher scores in active listening and delivery than they did in the active connecting domain; however, some MMs showed a higher proportion of active listening skills, whereas others scored higher on active delivery skills. Within specific practices, there was also considerable variation. Active connecting skills were less commonly observed, and applied in different combinations. On average, MMs exhibited just over three diverse types of active connecting skills per

visit. Just over one-third of visits (34.5%) employed four, five, or six types of these skills, and 12 visits (14.3%) employed one or none.

Figure 4: Performance by MM across domains, by percentage



Variation in MM performance

To add a further dimension to these findings, we looked at the age, education level, and average visit duration, captured by the length of the audio recording, for each MM.

Table 5 shows these variables together with MM performance across domains (p. 55), and Table 6 presents them in a correlation matrix (p. 55). These findings indicate longer average visit duration was correlated with the presence of multiple types of active connecting skills ($r=0.81$, $p < .001$). No other variables were highly correlated.

Table 5: MM variables and communication domains

MM	Age at job start date	Highest education completed (grade)	Average visit duration (mm:ss)	Active listening (proportion)	Active delivery (proportion)	Active connecting (proportion)
1	29.83	12	07:36	0.694	0.452	0.396
2	33.42	11	17:40	0.694	0.524	0.375
3	38.83	12	16:53	0.792	0.536	0.344
4	31.67	12	10:16	0.722	0.571	0.354
5	22.92	11	13:04	0.714	0.653	0.304
6	25.67	12	22:31	0.833	0.657	0.525
7	45.67	10	10:42	0.722	0.667	0.208
8	41.67	11	8:51	0.500	0.694	0.196
9	29.33	12	15:09	0.667	0.714	0.375
10	34.17	11	29:09	0.633	0.800	0.575
11	50.17	10	14:25	0.700	0.857	0.450
12	38.42	12	17:35	0.771	0.893	0.406
13	31.67	12	19:39	0.917	0.893	0.453
14	34.67	12	23:41	0.854	0.946	0.516

Note: Proportions shown within each individual domain (active listening, delivery, and connecting) are indicated out of a total of 1. For each MM at each visit, the number of strategies observed of the total available were summed, and an average of these scores was taken across all visits. These were subsequently converted to proportions within each domain. The relationship between performance across domains is not considered in this table.

Table 6: Correlation between communication domains and MM information

	Age	Education	Average visit duration	Active listening	Active delivery	Active connecting
Age	1.00					
Education	-0.61	1.00				
Average visit duration	-0.18	0.18	1.00			
Active listening	-0.24	0.45	0.40	1.00		
Active delivery	0.27	-0.06	0.52*	0.31	1.00	
Active connecting	-0.27	0.34	0.81**	0.47	0.42	1.00

**p<0.001

*p=0.05

Discussion

This analysis is the first of its kind to document communication practices in a rural home visiting programme, and specifically in a low-resource, community-based setting. There was high fidelity of best practices for communication observed in the visits, especially with regard to active listening and delivery. MMs used a variety of techniques to gather and reflect content from their clients; they consistently delivered relevant information, and engaged their clients through dialogue, ensuring their own understanding as well as verifying clients' understanding. Core intervention skills taught in training, and supported through supervisory structures, center on the ability of the MM to assess her client's situation and deliver a relevant intervention. These skills were widely observed.

As an opportunity to pilot a newly devised communication checklist, the HCSI, this study also reflects key areas for further application. Over 80% of home visits showed evidence of "suggestive" language, instead of didactic, directive statements, to equip the client with knowledge and at the same time give her space to make her own health decisions. While this figure is high, it is important to recognise that collaborative interactions encouraging client agency are central to the MM model, and should be aspects of every visit. Our initial exploration indicates that this method of observation can be used to comprehensively highlight strengths and limitations of implementer skills in communication and programme delivery.

While active listening and active delivery were consistently well-documented, active connecting was less so. Our findings indicate that, beyond core informational and conversational strategies, more complex rhetorical strategies were not readily observed across all MMs, or within all visits. Soliciting questions, using questions to probe understanding, reflecting feelings and concerns, and active connecting skills were

unevenly distributed across visits and MMs. Regarding active connecting skills, most MMs spoke about continuing visits and demonstrated general rapport-building; however, fewer explicitly articulated confidentiality, empathic statements, or offered anecdotes or similar experiences to relate to clients.

A necessary next step is distilling whether or not these less-frequently observed practices are “central” features of the intervention, or if their presence adds to the value of the intervention. Existing evidence shows that communication practices and styles form a crucial basis for building trusting clinical relationships, which can affect health service delivery and access. In peri-urban settings in South Africa, mistrust between clients and health providers and unclear expectations negatively influenced otherwise accessible and affordable care (Scheffler et al., 2015). In home visiting programmes in particular, research has shown that relationship quality has a significant bearing on participant experience of the programme (Bain et al., 2017). Furthermore, home visitor conscientiousness and home visitor-client compatibility have been found to strongly influence relationship quality and uptake (Brookes et al., 2006). While the contexts in which health-focused interventions are implemented vary widely, literature suggests that certain core principles of good communication between provider and recipient are standard across settings (Rollnick et al., 2008; Roter, 2000a). The HCSI may be overly inclusive—for example, not every visit may require an articulation of confidentiality. However, these data emphasise the importance of selecting core communication strategies to train and support MMs to employ to ensure a high-fidelity, standard set of expectations.

There are a few possible reasons for our finding that active connecting skills were less commonly employed. In examining variation between MMs, different personal styles predominated. Some MMs may master these social skills naturally, whereas others

struggle. Individual characteristics, diverse personalities, and differential motivation must be accounted for in interventions like Enable that rely so heavily on interpersonal engagement and trust. There is also some evidence indicating that maintaining professional boundaries can be a challenge for community-based health workers, who are part of the local community yet set apart through their training and employment (Kemp & Henderson, 2012). Future work with this sample will explore these challenges in a more nuanced way.

Furthermore, MMs may decide, or be asked by supervisors, to prioritise content over communication style, especially when they have other clients to visit. This decision might lead to the MM covering content in clear, explicit ways to ensure knowledge transfer and efficiency—while simultaneously undervaluing skills related to active connecting that might facilitate relationship building, as these skills are less quantifiable. Research about empathic communication in clinical and therapeutic relationships finds that building relationships requires “emotional labour” on the part of the practitioner, which is essential but takes time and effort to cultivate (Larson & Yao, 2005); thus, this observation may be a function of time and workload.

This last point speaks directly to an additional finding of ours: that MMs whose average observed visits were longer were also those with higher average scores on active connecting skills. While a range of factors might predict higher scores on active connecting skills—including communication fluency, closeness with the client, and command of intervention content—it is notable that conducting longer visits may encourage MMs to develop and engage a wider range of such interpersonal skills. Longer visits may also be a sign of stronger relationships, where MMs may be inclined to spend longer time with particular clients. It is important to recognise, however, that long visits may not always be possible, and more work is needed to understand barriers to

connecting with clients among CHWs. Upcoming analyses from this project will reflect on how MMs articulate in their own words the process of connecting to clients and building relationships, which may not be fully captured in these visit recordings. Furthermore, more work is needed to ascertain the effect of these softer skill sets on client behaviour change and intended health outcomes.

Implications for practice

The findings from this checklist analysis, across the MMs observed, show strengths in skills that are easy to convey in a training setting—such as using questions to gather information—and shortcomings in less tangible skills. Two core areas that might be most directly served by these findings are training and supervision. Adhering to a traditional, didactic training format has been shown to inhibit critical thinking skills and learning (Glenton et al., 2013). Supervision strategies must be sensitive and responsive to differences in the dosage, quality, and style of support given (Rotheram-Fuller et al., 2017). As such, extra opportunities for training and support, as well as differential support, should ideally be accessible and built into programme models. It is evident that a number of this programme's MMs struggled with some of the more complex interpersonal skills on which they were assessed; improving fluency in delivery might most easily happen through initial and/or ongoing training (Duthie et al., 2012). Employing the HCSI in a training setting—as a means of evaluating skills learned or structuring communication-based sessions—may be practical and valuable. The HCSI may also offer opportunities for supervisors to tailor feedback, or for funders to monitor programme implementation around skills translation and use.

The Enable Programme has adapted more hands-on supportive supervision strategies for MMs whose case folders show problems with delivering intervention

content, pairing them with high-performing colleagues who can provide guidance and support. However, Enable and other programmes might benefit from more closely examining implementer competence in action, and by adjusting ongoing training and supervision efforts to speak to specific, measurable needs in this area. In considering ways to increase fidelity, it is also important for programme models to set up realistic expectations for community health workers that accomplish programme goals while also addressing client needs. While a command of intervention content is key, implementers' communication skills have a central role in how clients respond to and engage with an intervention.

A practical method of data collection

The method we piloted also has implications for use in other community settings. Client-home visitor interactions have been assessed through directly observing home visits (Peterson et al., 2007), as well as coding video observations (Roggman et al., 2016). However, few studies from low- and middle-income countries have employed these kinds of systematic methods in home visit settings, in part due to logistical barriers. Our decision to use audio recordings addressed some of these concerns; using a mode of data capture that was portable and unobtrusive was essential, and we were able to smoothly integrate our data collection efforts with the typical delivery of the intervention.

Although audio recordings do have some disadvantages, for our purposes they were a feasible way to investigate what took place in the home setting (Brownson, 2017). Client-provider communication has been more widely documented and analysed in clinical settings in both high-income country (George et al., 2016) and low-income country settings (Abdel-Tawab & Roter, 2002; Jennings et al., 2011; Kilian et al., 2015; Kim et al., 2000; Watermeyer & Penn, 2009). However, our research shows that client-provider

communication skills can be measured in programmatic settings at the community level, where health-related consultations may exist outside of a traditional clinical setting due to resource constraints and overburdened health systems.

Limitations

It is important to note some limitations of this analysis. As these home visit recordings are “snapshots” of the long-term client-MM relationship—taken at a particular place in time, and not observing the client-MM interaction in its entirety—it is not possible to ascertain case history or a full sense of the relationship’s continuity beyond the sampled sessions. The longevity of a relationship may contribute to the building of trust and improve communication, and we recognise the potential for more contributing factors that may affect our findings, and that could be added to future iterations of this work. There is also the potential for desirability bias, if the MM decides to perform differently or better than she usually would due to an external presence; however, we aimed for our method of observation to be as discreet as possible (Breitenstein et al., 2010). Our use of audio transcripts instead of video recordings, selected for the reasons detailed above, nonetheless glosses over nonverbal communication cues that might invite a different perspective on the relationship or communication skills employed. Using transcripts also poses a complicating factor for working across a language barrier; even for coders who are familiar with Xhosa culture, and who consulted Xhosa colleagues for further questions or clarifications about meaning and translation, there are still potential limits to how conversation is phrased, a topic is framed, or an exchange understood (Xian, 2008). An upcoming replication of the HCSI plans to utilise Xhosa-speaking research assistants to complete the checklist using audio recordings of home visits that will then be quality-checked, reducing the resources

required for transcriptions and translations. Finally, although we developed the HCSI based on “best practices” of communication and programme-specific training skills, it is possible that other cultural, social, or contextual realities may influence communication styles. Further iterations of the HCSI might solicit perspectives from supervisors and CHWs to integrate their views or to tailor this checklist to suit programmatic needs more specifically. Nevertheless, this analysis establishes important formative work in the development of a checklist for analysing communication strategies, and affirms the viability of more granular, detailed modes of implementation research at a household level.

Conclusion

Home visit settings, while often overlooked, are important sites of programme delivery, especially as community health programmes expand. The findings presented here from the newly-piloted HCSI offer novel insights for researchers and practitioners alike about how to approach monitoring and fidelity in these settings, and how capturing communication strategies can be a specific and measurable way to gauge success in programme delivery at a more detailed level.

References

The references for this article can be found integrated into the final References section of this dissertation, beginning on page 169.

Chapter 4: Instructive roles and supportive relationships: client perspectives of their engagement with community health workers in a rural South African home visiting programme

Introducing Article 2

This chapter contains the second of four articles in this dissertation. In this paper, I focus on gathering the perspectives of 26 clients of the Enable MM Programme, and ask about their experiences with their MMs and the programme more generally. Clients shared both educational benefits, and more broad-based supportive care, that they received from their relationships with their individual MMs. They also voiced their willingness to be honest with MMs about constraints to following advice, or decisions against doing so. The article discusses the implications of client empowerment, engagement, and involvement in implementation research of community health programmes.

This article was submitted to *International Journal for Equity in Health* in June 2020, and includes the following co-authors: Sarah Skeen, Bronwyne J. Coetzee, Sarah Gordon, Vuyolwethu Notholi, Julia Bishop, Emma Chademana, and Mark Tomlinson. It is reproduced in this dissertation, in the same style as it was submitted for publication.

Abstract

Background: CHW programmes have been positioned as a way to meet the needs of the most vulnerable, and current global health narratives also emphasise their adaptable nature to meet growing health burdens in low-income settings. However, as CHW programmes adopt more technical roles, the value of CHWs in building relationships with clients tends to be overlooked. More importantly, these programs are often reframed and redeployed without attending to the interests and needs of program clients themselves. We set out to gather perspectives of programmes and CHW engagement from clients of a maternal and child health program in rural South Africa.

Methods: We conducted 26 interviews with pregnant or recently-delivered clients of the Enable MM programme between February-March 2018. A trained research assistant conducted all interviews in the clients' home language, isiXhosa, after obtaining informed consent. Interviews, translated and transcribed into English, were organised and coded using ATLAS.ti software and thematically analysed.

Results: Findings indicated that clients engaged with their individual MMs through generally positive home visit sessions that enabled instructive, educational interactions as well as more broad-based support. Relationships were developed within the home visit setting, but also extended beyond routine visits, especially when clients required further instrumental support. Clients further discussed a sense of agency gained through these interactions, even in cases where they chose not to, or were unable to, heed their MM's advice.

Conclusions: These findings point to the need to bolster training and support for CHWs in similar programmes, especially as deepening relationships may be key for encouraging behaviour change. They also emphasise the importance of integrating more channels for client feedback into existing programmes, to ensure that clients' voices are

heard and accounted for in shaping ongoing engagement within the communities in which these programmes operate.

Introduction

Historically, CHW programmes were conceptualised as a way to meet the needs of the most vulnerable. The 1978 Declaration of Alma-Ata, which formally laid the foundations for countries to mobilise CHW programmes, was based on social justice, health equity, and empowerment of local communities and capacity (Rifkin, 2018). However, these programmes, as they were initially widely rolled out across a range of LMIC settings, quickly became subject to debates around their financing, implementability, and societal value. In many countries, they were dissolved to make way for market-driven solutions to health care (Perry et al., 2014).

Currently, in the context of a global shortage of health care workers, and a rising demand for services, community-based approaches to health service delivery are being re-evaluated as a way to fill this gap (Schneider et al., 2016). In this current iteration, deploying CHWs is viewed as a more technical solution to poor coverage and care for the health system, and a means for countries to achieve ambitious targets as set out in the SDGs and the drive for Universal Health Coverage (Tangcharoensathien et al., 2015).

Globally, the roles of CHWs are malleable and not easily defined. In most settings, CHWs are trained lay health workers—who operate either within or in conjunction with, or outside of the formal health (state) system, who are typically members of the communities in which they work, and who are seen as being able to reduce the burden on under-resourced and overstretched health professionals (Deller et al., 2015). Part of reducing this burden comes through task-shifting: the systematic

delegation of tasks from one cadre of health worker to another, often less professionalised, cadre (Lehmann et al., 2009). In times of crisis, such as during the emergence of the HIV/AIDS epidemic in sub-Saharan Africa, task-shifting has been essential in expanding and re-purposing the workforce (Kredo et al., 2014). For CHWs operating across programmes with different health focus areas, however, task-shifting has become the norm. As programmes become more broad-based and horizontal in their framing, there is also a risk of “task-piling” or “task-dumping” where CHWs take on increasingly more responsibilities previously completed by nurses or not at all (Dambisya & Matinhure, 2012).

This shift has ostensibly been driven by the needs of health systems, and not necessarily by the people served by CHW programmes. There remains little consensus on what the beneficiaries, or clients, of CHW programmes actually require and want from programmes, as few studies incorporate their perspectives (Hackett et al., 2019; Roman et al., 2012), especially in LMICs (Bain et al., 2017). As a result, there remains a stronger focus on evaluating delivery mechanisms and health outcomes, than on the processes through which clients take up new information and connect with their CHWs (Kim et al., 2015). While both areas of focus are important, these client perspectives can be just as important as more commonly-measured health outcomes (Pallas et al., 2013), in revealing priorities, capturing reasons for engagement or dropout (Perales et al., 2018), or contextualising challenges in implementation.

The data we do have from other clinical settings, and different types of health providers, point to the centrality of the relationship in clinical encounters. Qualitative research in particular has provided rich data on how clients experience, and respond to, health encounters (Brydges et al., 2016; Foster et al., 2010). A systematic review on patient perspectives of quality of care across formal health delivery settings found that

patients most commonly identified communication, access, and shared decision-making as important in clinical interactions (Mohammed et al., 2014). This finding echoes work by health practitioners and researchers highlighting the importance of shared decision-making and improved communications as a means to facilitating a sense of respect and agency in patient-provider interactions (Joseph-Williams et al., 2014; Kaba & Sooriakumaran, 2007). These relationships and experiences drive whether or not patients are motivated to continue to seek care, and ultimately have bearing on whether health outcomes can be improved, especially in LMICs (Mannava et al., 2015).

A lack of evidence prevents us from understanding to what extent clients of CHW programmes similarly benefit from, and rely on, relationships as a means to support them to achieve better health outcomes (Maes et al., 2014). We can nevertheless hypothesise that these relationships are equally, if not more, important in these programmatic frameworks given the community-embedded nature of the CHW role. If this is the case, then a predominant focus on task-shifting and increasing workloads for CHWs may in some cases hinder the establishment of these formative relationships. Without a more nuanced understanding of how clients experience and engage with their CHWs, we may be missing critical information about how to make these programmes more effective, how to meet the needs of the most vulnerable, and how to ensure that shared decision-making is a reality in health programmes.

To build a more comprehensive picture of mechanisms through which CHW programmes may bring about change, we need to ask clients themselves about their experiences with and perspectives on their CHWs, as the main interface with the programme, and the relationships they maintain. This paper aims to explore how clients in a maternal and child health programme in rural South Africa experience their engagement with their CHWs.

Methods

Ethical approval for this study was granted by Stellenbosch University's Health Research Ethics Committee (N16/05/062).

Design

This study was descriptive in nature and utilised semi-structured interviews with pregnant women and recently delivered mothers who were clients of the Enable MM programme, further referred to as Enable.

Setting

The O.R. Tambo District, where Enable is based, is among the poorest districts in South Africa. In addition to high unmet need for health services, many of Enable's clients live in remote rural areas, where accessing health facilities can be challenging and resources unevenly distributed (Massyn et al., 2017). With regards to maternal and child health, the O.R. Tambo District has significantly higher rates of maternal and neonatal mortality than the national average (Massyn et al., 2017). A large number of mothers and caregivers are able to access government child support grants, which many of them rely on for basic child care needs given high rates of unemployment and rural-urban migration (Hall & Budlender, 2016).

About Enable

Enable is a home visiting intervention focused on maternal and child health and nutrition; the programme has been operating in the O.R. Tambo District since 2016. The programme uses the Philani MM model, which was originally designed and implemented by Philani Nutrition Project in peri-urban Cape Town (Rotheram Borus et

al., 2011). In this model, MMs are identified by established community leaders as mothers who have managed to raise healthy children despite significant adversities. Recruited mothers undergo a six-week training, followed by an evaluation, before a subset is selected to work in their own communities. MMs recruit and follow up pregnant women, as well as specifically targeting families with underweight children, to provide supportive, preventive care in the home for up to five years. While Enable adheres to Philani's model of intervention training and content, the programme was applied in a new rural setting, in a different organisation (Laurenzi et al., 2019), in what is known as a "social franchise" of the original model. While a MM may have up to 50 or 60 maternal clients, each client is enrolled and visited by only one MM, although these visits occasionally involve supervisors or programme coordinators. MMs are distributed across a wide geographical area, each covering their own set of clients within a given village.

Recruitment

A list of all clients in the Enable Programme was obtained from programme staff. In order to ensure a diverse sample of interviewees, two clients per MM were included as a target sample. The first author (CL) randomly sampled clients from each MM's caseload, while ensuring variation in characteristics by age and number of children. Alternative clients were contacted in cases where a client was uninterested or unavailable.

Data collection procedures, transcription and translation

Interviews were conducted between February and March 2018 and were arranged and completed by an isiXhosa-speaking researcher with extensive qualitative interview

experience (VN). CL devised a draft interview schedule and met with VN to discuss each question and refine or clarify phrasing where needed. The semi-structured interview schedule was then finalised and used to guide interviews. Informed, written consent was obtained before interviews began, and all interviews were conducted in participants' homes and audio-recorded with consent. Both informed consent and the interview itself were conducted in participants' first language, isiXhosa. Interviews averaged one hour duration each. Audio recordings were removed from the recording devices at the end of each day, transferred onto a password-protected computer, and later uploaded to a secure cloud-based folder. Throughout the interview period, CL and VN discussed progress 3-4 times weekly, and VN shared any challenges that emerged during individual interviews as well as patterns she observed across interviews.

Between April and October 2018, an experienced isiXhosa-speaking team reviewed audio recordings, and simultaneously translated and transcribed interview content into English. Specific words or short phrases were left in isiXhosa on a case-by-case basis to preserve meaning, and alternative definitions or explanations were added where appropriate. CL met with the transcription team regularly to discuss progress. A senior member of the transcription team checked 50% of transcripts over the course of the transcription period for quality and accuracy.

Data analysis

Data were organised and coded using ATLAS.ti qualitative software. All transcripts were read closely before coding, and were later coded inductively (Thomas, 2006). Data, while aligned with questions in the interview schedule, varied substantially. A total of 98 codes were initially developed to summarise content across the transcripts. Following several rounds of collation, review and refinement, 51 codes formed the final

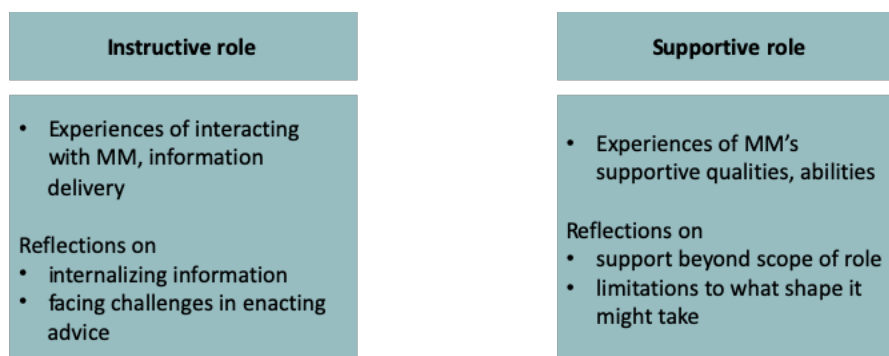
code list. CL was the primary coder, and a second independent coder (SG) read three interviews (11.6%) after which common codes and emergent themes were discussed.

Results

Participants (n=26) were all female, and on average, 26.9 years of age (SD = 5.77) at the time of the interview. Nearly 60% of participants were enrolled as clients in the first six months of Enable's implementation. Ten participants were first-time mothers (38.5%), and eight were married (30.8%).

The coded data were grouped into clear superordinate themes that clearly reflected core MM roles (Figure 5). These included instructive roles (clients' experiences and reflections on MMs in instructive contexts) and supportive roles (clients' experiences and reflections on MMs in supportive contexts).

Figure 5: Overview of codes from client interviews



Instructive roles: communicating information and encouraging behaviour change

In speaking about interactions with their MMs, most clients shared experiences about new information learned and internalised, and how this information was relayed (i.e., the mode of instruction). Clients also reflected on the impact of this education—what it

meant for their child's health and their own sense of agency, as well as challenges to enacting this advice.

Experiences of instructive encounters. In their interviews, clients affirmed that learning new information about their own and their child's health was a central part of the MM-client interaction. Clients emphasised the skills of their MMs in conveying new instructive information, and ensuring client understanding at regular intervals:

PID13: When she arrives, talking to me, she explains it and asks if I heard what she said.

Interviewer: Okay, why it is important for her to ask you if you heard what she was saying?

PID13: It is important to me because I have to know it...Because it's me who agreed to work with her, so I have to know it.

In addition to sharing strategies for learning, clients indicated that they felt compelled to satisfy their obligations to the MM-client relationship.

Not all instruction was described as verbal. Clients highlighted the importance of hands-on activities and examples, saying they learned better when their MM acted something out:

PID6: She also acts some other things, I mean she has got many examples...and her examples are clear and corresponding to what she is saying.

When MMs supplemented their instructions and explanations with actions, clients described grasping new knowledge more quickly. In certain cases, this also applied to deciding which information was most important. One client spoke about filtering information through cues from her MM:

PID21: When she emphasises something, she looks at you directly and says "hey, I'm serious about what I'm telling you, as you always like not to take things not seriously" so that is what I notice with her, and say hey, [my MM] emphasised this thing...

Interviewer: Okay, alright. You catch it even if you were not going to catch it when she is looking at you directly?

PID21: Yes, and know that at least maybe this one is important.

These instructive strategies were often tailored to what a particular client needed to learn and take up new information and ensure thorough understanding.

Reflecting on and engaging with information delivery. Beyond sharing experiences and examples of receiving information from their MMs, clients also reflected on the role of this information, and the relationship context in which it was delivered. They spoke about why they decided to internalise and act on advice, or not, how they engaged with new health information, and when they faced challenges to taking action in line with their MM's advice.

Internalising information. Clients compared their "current" selves to who, and how, they had been before being enrolled in the Enable Programme, detailing the process of gaining knowledge and confidence.

PID1: As a person, you learn till you die, you see? So there are so many things that I learned. I didn't know that you have to wash your hands before you touch a baby's bottle, then wash the bottle and prepare food for the baby, I didn't know that. Even feeding the child, I thought that you just feed the child...I didn't know the motive behind it, you see...So after she came and explained to me about breastfeeding, telling me that breastfeeding is very important, even the scale [taking the child's weight] is very important, telling me that the child must never miss the scale dates [at the clinic], I became alright, I saw myself as a good person and I did things the way she told me to.

Another client spoke about adopting new information to make informed decisions, and why she considered her MM as a credible source of information:

PID24: I mean like as a person what you are talking about becomes visible from your facial expression, you see from the face that, “okay, this person knows what she is talking about and she is living it”...She is living with what she is saying, you see...And [you] notice that hey, maybe this thing is good, so you rather try it and [it] helps you after trying it and you see that, no these things that are said by this person are good, so let me follow them and be close to her so that when she talks I do, every time she talks I do what she is saying.

For some, this credibility also came with the MM’s approach, as one client described how her MM “would give compliments saying ‘no my child you are listening carefully’ because she teaches those things in a good way. You will never understand someone who came to you with attitude” (PID17). Clients also shared a renewed sense of external accountability, and anticipation, from having a monthly or bimonthly visitor who they respected:

PID6: I once had that thing on my previous children...That thing of not going to the clinic. But having that mentality of there is no one who is going to ask me. Now I have that feeling, wishing that she can arrive quickly and also see that the weight of my child increased now, that time there was a scale.

These reflections on assessing and internalising information revealed clients’ abilities to engage with their MMs, which fostered important changes in their own knowledge and practice with their infant.

Facing challenges in enacting advice. These interchanges also enabled clients to recognise their own agency, even when they did not fully follow the MM’s counsel. A young mother spoke about the strength she was able to draw from conversations with her MM:

PID2: When I forgot, she reminds me and say “did you do what I told you” and if I didn’t do it I say no I didn’t do it “why you didn’t do it?” so deep inside that thing is encouraging me to continue doing it till I get used to it because it also helps me, at the end it’s me who

will be in [trouble]. So by doing that, she is strengthens me because she is the one telling me things.

Another client spoke about needing to make a decision about breastfeeding based on her own needs, despite understanding its benefits from her MM:

PID25: What was challenging, it was when she asked me to breastfeed for six months but I couldn't, because I was going back to school and I was going to leave him behind so I was not able to do that... yes, she told me it is good [important] but I couldn't, and I was like, 'she will forgive me on this one.'

By acknowledging her MM's ability to "forgive" her, this client also described a sense of respect in the relationship, indicating her MM would not condemn her for her decision. Other clients similarly shared challenges to enacting certain advice from their MM due to financial or logistical constraints. Responding to a question about barriers, one client spoke about lacking funds for medicine recommended by her MM:

Interviewer: Have you tried to do some of the things she tells you or teaches you, but because of the circumstances you find that you are unable to fulfil them?

PID22: Yes, I don't fulfil some of the things she teaches me...it is on things that we need to eat [medicines we need to take] when we are not well, so I am unable to reach them because there is no money.

Supportive roles: building relationships and sharing burdens

In describing and reflecting on their relationships with their MMs, clients also revealed how the Enable Programme provided a deeper sense of social support, through the mutual respect, responsiveness, and attentiveness of their MMs. This relationship, built over time, was described as valuable and distinct from other types of relationships.

Experiences of mutual respect and familiarity. Sharing their experiences with MMs, clients iterated that respectful, supportive interactions were essential to their perspective of the programme and their MM relationships. They described supportive qualities that their MMs practiced in typical engagement. Consistency and continuity were highly valued:

PID24: She is not a person that changes having different faces every day, she remains the same, and she is always humble and I can ask anything that I want to ask from her. She is just a person like that, I can even call her and ask how is this going, what must I do now.

In addition to experiencing support through warm interactions with MMs, clients spoke of knowing a MM through her community embeddedness—reiterating a sense of security, trust, and familiarity that comes with health workers operating in their own communities.

PID5: Since we know her, she is from here, when we have something that we do not understand, we just talk like [MM name], what it is about a certain thing, just like that because we know her. If you can come as another person [from outside the community] maybe we can have things that we are afraid of, but we are not afraid of her.

Where this support was tangible, it further affirmed the role of a MM, showing how she was able to build on existing trust with additional resources.

PID17: She is diligent to this job but even before she started doing this job she was diligent, she cannot manage to watch someone suffering, even if it's not her family member, that is her nature...most families here are getting social grants because of her.

The supportive qualities revered by clients centered on more personal, community-based attributes, facilitating their acceptance of the MM programme.

Reflecting on the scope of the MM role. Clients also reflected on the importance of having a supportive peer and health paraprofessional in their lives. Many women described a tangible feeling of support that extended beyond what they saw as the purview of the MM; a few women were stricter about drawing boundaries around the role of the MM.

Extending support beyond the job's requirements. One client described a surprise visit from her MM, who arrived on her day off to check on the client's progress following a health complication:

PID11: Hey she once surprised me, she came on a Saturday the time my stitches where damaged, I called her Friday evening and she came, shame, on her off-duty day, she was telling me that "I'm not working but I will come just for your sake".

Interviewer: How did you feel about that, like it was not her day on duty but still when you are in trouble she comes to help you?

PID11: It's kind of...I took her as someone who is dedicated to her work, she does not have that "I'm supposed to be doing my things" and all that, but she can sacrifice her time and do what she [is] supposed to be doing.

Another client echoed a similar sense of feeling supported outside of typical visits, with a broader household audience absorbing her MM's advice:

Our Mentor Mother is very diligent, I love her...it doesn't matter where she is, if she is at work, she would say after work I will come and listen to what you are calling me for, here at home we like inviting her even if we just sitting we will just call her (PID14).

These interactions showed a willingness of the part of the MM to work outside the structure of her job, and to put time into fostering positive relationships, even if it meant sacrificing her own time—something that clients felt humbled by.

For particularly vulnerable clients, extended support could act as a lifeline. One young mother who lacked a broader family support system stated, *“I can say she is more like a parent to my child more than me.”* When prompted further, she explained:

“Because she can advise and I know nothing about a child, saying this is how to take care of a child, telling me about the stages of a child, telling what to feed a child when a child is at which stage and breastfeeding when she was still breastfeeding” (PID2).

Another young mother, who was pursuing her further education away from home without any support from her child’s father, described the emotional support her MM provided:

“That is what I need, I need somebody, when I cry I feel like there can be someone to give me something positive, as I’m negative and she is always positive” (PID11).

Despite the high level of poverty in the programme catchment area, some clients were worse off than their peers because of lack of support, child disability, or living in extremely remote households. One client, who cared for a disabled child completely on her own, shared the extent of her MM’s support:

PID26: She would say, ‘never lock yourself with poverty alone here, when you have nothing [to cook] you must phone.’

Interviewer: Okay, how does that make you feel, someone saying such things to you?

PID26: I feel happy sister, because these days there is no one who can care for you like that.

This client and a number of others reflected on times when their MMs brought a hot meal or a fare to pay for transport to a health facility—reiterating that this support sometimes took on an instrumental role beyond the emotional and informational roles that MMs played.

Limitations to the scope of the MM’s supportive role. In a few cases, clients were less inclined to seek additional support from their MMs. These individuals were aware of

limitations of MMs' roles and questioned the extent of MM confidentiality while also being embedded in the same community. When one client was asked if she readily discussed personal struggles with her MM—such as relationship problems, substance use, or mental health—she responded that she saw these as separate from the programme's scope:

PID1: She took care for us while we were pregnant and she is still taking care of us as we have children, so I just think those stress issues are just...it's just a talk after she finished her duties, you see.

Interviewer: Okay.

PID1: Like telling her that me and my husband we had a problem and I was hurt here and there, so just a talk...It's not part of her work when I think.

Some clients also felt that there was a limit to the support they could seek from MMs, even if confidentiality was discussed, as they came from the same small, tight-knit community. One client described a hypothetical situation:

PID24: So I would share my problem with you, but since you know me you share it to your loved one, and that one share to another one...So that is what tells me that my problem is my problem, I cannot share it to a Mentor Mother.

These perspectives about how MM roles might be limited reflected a sense of caution and care from clients, and highlighted diverse approaches to the client-MM interaction.

Discussion

We explored clients' experiences of a home visiting programme for maternal and child health to gather perspectives on the programme, and more specifically, on clients' relationships with their MMs. This analysis helps to identify potential areas for strengthening programming from the perspective of those receiving services directly. It

also offers a chance to consider the trade-off between accomplishing tasks and cultivating relationships in similar CHW programmes.

Client engagement as a window to behaviour change

Overall, client perspectives were positive and reinforced the aims of the Enable Programme. Clients shared reflections on having an ongoing relationship with their MM, and what this engagement meant for their health and wellbeing. These relationships were central to their experience of Enable, and clients described ways in which these relationships motivated them through a combination of education and encouragement—helping increase their confidence in health-related decision-making. These findings on supportive relationships and enabling encounters map onto existing understandings of how lay health worker interventions activate behaviour change (Hill et al., 2008; Philani, 2016), as well as how shared decision-making and client-centered communication in clinical encounters can engage clients as agents in their own health (Abdel-Tawab & Roter, 2002; Joseph-Williams et al., 2014; Kim et al., 2002). They also speak clearly to the World Health Organization’s framework of integrated people-centered health services (World Health Organization, 2016) which echoes the need for “care delivered in an equal and reciprocal relationship” (p. 4).

These perspectives also raise the question of how, and why, these kinds of relationships and interactions are possible in community health settings. Prior research on CHWs has identified obvious advantages that community members may have in enacting these roles: these relationships can take place outside of clinical hierarchies, with someone from a similar or same community (Perry et al., 2014). They may also provide more individualised, thorough care in non-formal health settings (Rachlis et al., 2016). As these data indicate, the supportive nature of the relationships between home

visitors and clients may be able to create a mechanism for bidirectional accountability, by fostering a sense of mutual respect and responsiveness, and encouraging clients to work towards agreed-upon goals (South et al., 2013). These relationship qualities are far removed from more stressful, power-imbalanced interactions in formal health facilities that have been reported in many rural and LMIC settings (Bohren et al., 2019).

Limitations in client-CHW relationships

Importantly, not all relationships were described as equally positive. A small subset of clients shared reservations about their MM, related to confidentiality concerns or lack of clarity around the scope of the programme. It is also important to note that not all CHWs are equally committed, or receptive to training, and that some CHWs may struggle to build durable, reciprocal relationships with all of their clients (Brookes et al., 2006). Furthermore, even when the scope of a MM's role is well-defined, clients themselves may elect to engage in a more bounded, professional relationship with home visitors.

These client responses can also be seen as a strength of the programme model—enabling clients to feel able to exercise agency, challenge advice that does not work for them, and find ways to compromise where possible. This was evident even in data from clients who spoke warmly about their MMs, but who faced additional barriers to adopting different strategies. For some mothers, fully taking on their MM's advice—by planting their own vegetables, or adhering to a plan to exclusively breastfeed—was more challenging in their specific circumstances, and not always an act of resistance or reluctance. That clients sometimes did not follow their MM's advice could be seen as contrary to the programme's aims, by stalling progress towards certain health goals. In some cases, this was out of necessity, not choice. However, these modes of engagement

are also critical for empowering clients to find their own solutions, especially when evidence-based programme goals confront context-related constraints.

Listening to clients

This analysis adds an important perspective, largely missing from the literature on CHW programmes and task-shifting, by incorporating the voices and priorities of clients. Clients' perspectives provide insight into the kinds of services and interventions they prioritise, and thus offer a way to map these priorities against programmatic goals. For instance, supportive relationships are often seen as a means to achieve intended programme outcomes in lay health worker interventions (Bain et al., 2017). However, we found that they also provide their own form of intervention through linking clients to broader support networks beyond the health-specific aims of the programme. The supportive relationships that clients described were, often, more deeply personal stories about how MMs provided information that made them feel capable of raising an infant alone, or able to rely on another person for a hot meal when they were in desperate circumstances. These findings also suggest that even when information and activities are present and prioritised by intervention designers, supportive relationships are at the core of these programmes, and the ability to draw on existing bonds is what makes programmes more effective. Clients' characterisations of these relationships, and how they engaged their MMs over time, provides fresh insights into how evidence-based community health programming can and should draw on principles of equity and respect in theorising how behaviour change can happen.

These perspectives can also be contextualised with other types of research. Interestingly, these findings fill some gaps in concurrent research published by our team, with the Enable Programme, on MM-client relationships (Laurenzi et al., 2019). Our

team obtained consent from clients and MMs to audio-record individual home visits with 85 clients, and analysed recordings using a novel communication skills checklist capturing existing communication skills. While skills showcasing active listening and interactive delivery skills were frequently observed in visits by all MMs—skills that, in this analysis, would be more closely linked with fulfilling instructive roles—communication skills related to “connecting” and relationship-building were less common. The qualitative client interviews in the present analysis, however, suggest that the MM’s supportive role is highly valued by clients, if not universally observable across a cross-section of home visits. Many of the interviews pointed to non-verbal cues and other “connecting” factors contributing to relationship building that are not as easily captured in audio recordings. As such, triangulating diverse sources of data and/or adopting a mixed methods approach for future studies may provide more contextualisation and a closer read of these experiences at the household level.

Relatedly, this analysis raises interesting questions about fidelity and adherence to the programme: as noted above, clients did not always listen to their MMs, nor did MMs always adhere strictly to their job description. While measures of fidelity and adherence are sometimes used to explore the effectiveness of CHW programmes, qualitative data may be able to highlight where these defined measures can fall short. Clients were clear that their relationships were able to provide them a sense of agency and collaboration in the routine visits. Less evident, but still present in these findings, was the flexibility that MMs themselves employed to support clients and build trust—even when these actions occurred outside of the bounds of their job’s expectations. Other research has documented this flexibility and adaptation that CHWs use to support their client relationships (O’Brien et al., 2012).

Implications for practice

These data, directly gathered from clients of the Enable Programme, offer insights into how to tailor specific delivery aspects of this particular programme. They also provide lessons for wider-ranging programming and policies surrounding adapted models of community health programmes in LMICs, specifically attuned to implementer-client relationships.

Firstly, our findings point to implications for training and programme delivery. Programmes that leverage a more complex range of skills, including counselling skills, in training have been found to produce better quality of care (World Health Organization, 2018a). However, our analysis also suggests the importance of avoiding unnecessary task-shifting, and embedding an emphasis on relationship-building into programme and training manuals. Working with populations in low-resource settings may also require a broader set of support-related skills and more flexible, responsive solutions in the field that can be established by training focused on self-efficacy and CHW empowerment (Wiggins et al., 2013), and sustained through experience and supportive supervision (Ludwick et al., 2018). While a review of CHW training found that curricula frequently covered interpersonal skills and managerial skills (including relationship building), training processes were found to vary widely, in contrast to high standards set for other health care professionals (O'Brien et al., 2009). Training should, especially in LMICs, be tailored to fit the strengths of the CHWs themselves, as well as the contexts in which they operate. Prioritising high-quality, routinely practiced skills related to implementer competence in training settings is imperative as CHW programmes continue to grow (Breitenstein et al., 2010).

Secondly, these findings indicate the need to integrate more regular client feedback through channels that can feed into practice. While MMs typically provide

individualised services to different clients based on need and ability, it may also be important for MMs to communicate the scope of their possible role and set boundaries from the time of client enrolment in the programme (Allen et al., 2016). This practice may prevent later confusion or misaligned expectations. For those clients who attempt to implement changes but are financially unable to do so, additional support may be needed to pick up these cases and help clients identify solutions. Even if MMs are aware of client challenges on an individual basis, common challenges might be able to be identified through support groups, community forums, or health events. From a research perspective, community-based participatory research may present a more comprehensive way to address disparities and empower programme beneficiaries in implementation research, while simultaneously producing more effective programme content (Wallerstein & Duran, 2010). These methods present further possibilities for broader kinds of stakeholder engagement as programmes are newly developed and expanded. Collaborative processes, designed to ensure that a programme meets beneficiaries' and implementers' needs, are emerging as critical in intervention development, adaptation, and evaluation (Kangovi et al., 2016; Molapo et al., 2016). These processes include concepts of human-centered design and community advisory panels; they may be especially important for ensuring social franchises, for example, can be directed by users' opinions and needs. However, more research incorporating these methodologies and specifically engaging clients in their own health is needed.

Conclusions

Our study found that clients of a maternal and child health home visiting programme formed relationships with their home visitors based on instructive, supportive care. We also found that most clients also felt a sense of agency and

confidence from these interactions, even when they were unable or unwilling to fully adhere to health counsel. As community-based health programmes are increasingly relied on for increasing access to health care, conscious decisions to solicit the perspectives of clients should be prioritised to maximise the potential of these programmes.

References

The references for this article can be found integrated into the final References section of this dissertation, beginning on page 169.

Chapter 5: Balancing roles and blurring boundaries: Community health workers' experiences of navigating the crossroads between personal and professional life in rural South Africa

Introducing Article 3

This is the third of four articles in this dissertation. In this paper, I explore the experiences of ten MMs from Enable's first cohort, in order to better understand how they carry out their roles and navigate the benefits and challenges of working in their own communities. While there were high levels of satisfaction among MMs regarding their roles in the community and their engagement with clients, there were also entrenched challenges they faced. Many MMs identified strategies to navigate between their own personal lives and the professional demands they faced in their job—yet this distinction was not always clear, nor easy to maintain. This article reflects on the demands that are placed on these workers, who are mostly women from low-resource communities themselves, and suggests three types of solutions that might contribute to building capacity and support networks for CHW programmes.

This article was submitted to *Health and Social Care in the Community* in May 2020, and includes the following co-authors: Sarah Skeen, Stephan Rabie, Bronwyne J. Coetzee, Vuyolwethu Notholi, Julia Bishop, Emma Chademana, and Mark Tomlinson. It was returned to me on 15 July 2020 with two favourable peer reviews recommending minor revisions. The revised version, submitted on 24 July 2020, is reproduced in this chapter.

Abstract

As demand for health services grows, task-shifting to lay health workers has become an attractive solution to address shortages in human resources. CHWs, particularly in low-resource settings, play critical roles in promoting equitable health care among underserved populations. However, CHWs often shoulder additional burdens as members of the same communities in which they work. We examined the experiences of a group of CHWs called MMs working in a maternal and child health programme, navigating the crossroads between personal and professional life in the rural Eastern Cape, South Africa. Semi-structured qualitative interviews (n=10) were conducted by an experienced isiXhosa research assistant, asking MMs questions about their experiences working in their own communities, and documenting benefits and challenges. Interviews were transcribed and translated into English and thematically coded. Emergent themes including balancing roles (positive, affirming aspects of the role) and blurring boundaries (challenges navigating between professional and personal obligations). While many MMs described empowering clients to seek care and drawing strength from being seen as a respected health worker, others spoke about difficulties in adequately addressing clients' needs, and additional burdens they adopted in their personal lives related to the role. We discuss the implications of these findings, on an immediate level (equipping CHWs with self-care and boundary-setting skills), and an intermediate level (introducing opportunities for structured debriefings and emphasising supportive supervision). We also argue that, at a conceptual level, CHW programmes should provide avenues for professionalisation and invest more up-front in their workforce selection, training, and support.

Introduction

Recent estimates indicate that by 2030, there will be a global shortfall of 18 million health workers, primarily in LMICs (Organization, 2016). As demand for health services grows, task-shifting to lay health workers has become an attractive solution to attempt to close these gaps (Fulton et al., 2011; Okyere et al., 2017). A well-developed evidence base supports the effectiveness of lay CHWs in addressing areas of maternal and newborn health (Rotheram-Borus et al., 2011), HIV/AIDS support (Mwai et al., 2013), psychosocial support (Nyatsanza et al., 2016), and child nutrition (le Roux et al., 2014; Yousafzai et al., 2014), among other domains. Furthermore, research has documented the potential fiscal benefits of task-shifting (Seidman & Atun, 2017), promoted modes of strengthening existing community-based programmes to deliver quality interventions at scale (Perry et al., 2017), and raised key considerations and challenges for policymakers (Deller et al., 2015).

Much of the literature about CHWs describes a generally motivated workforce (Greenspan et al., 2013), buoyed by a sense of purpose and dignity (Swartz & Colvin, 2015) and an opportunity to earn an income while helping their peers (Singh et al., 2015). Qualitative accounts of CHW programmes indicate that CHWs readily take on additional roles, and are mobilised by a sense of service and deeper connection to their clients (Busza, Dauya, Makamba, et al., 2018). Particularly in LMICs, CHWs have emerged as critical to promoting equitable care, serving families in regions that are typically underserved by formal health systems (Sommanustweechai et al., 2016). Most CHWs work in their own communities, making them well-suited to connect to their peers; this proximity also facilitates broader acceptance of CHW initiatives (Scott et al., 2018). The majority of CHWs, an estimated 70% globally, are women (Lehmann & Sanders, 2007).

The CHW role also requires individuals to shoulder specific responsibilities and expectations (Mundeva et al., 2018). While CHWs are often selected based on demonstrated interpersonal competencies, previous experience, and/or geographic location, they typically undergo limited pre-service training (Lehmann & Sanders, 2007), and as a result may lack the requisite professional skills and support to navigate the complexities of their roles (Pandey & Singh, 2015). In transitioning from a community member to a trained paraprofessional, CHWs may be unprepared to negotiate local power dynamics and how this may shape clients' health care access (Lehmann & Gilson, 2012). Many CHW programmes are also situated in resource-constrained settings, with poor health infrastructure, which may complicate their experiences of supervision, or demand more from them personally to attain programme goals (Rotheram-Borus et al., 2017; Satti et al., 2012). CHWs may underestimate the challenges of addressing the health needs of their peers, and the additional emotional toll this may take.

These realities challenge many health care workers in demanding circumstances; however, they can be more pronounced for CHWs, especially in LMICs. These circumstances also call into question the idea of CHWs as a "tool" to solve entrenched problems, which has been the de facto response in global health policy (Perry et al., 2014). Considerations about how CHWs navigate community spaces are essential for implementation research seeking to track the effectiveness, long-term sustainability, and scalability of community-based health interventions (Pallas et al., 2013). Although most CHWs are embedded within the communities they serve, there is limited research on how their performance is linked to, and interacts with, the context in which they work (Kok et al., 2015). Furthermore, the voices of CHWs themselves have been largely absent from this body of literature (Maes et al., 2014; Swartz, 2013). Some researchers have begun to explore CHWs' perspectives on their roles and their motivators (Swartz &

Colvin, 2015), and how they navigate the dual imperatives of working within their own communities while providing services as paraprofessionals (Pandey & Singh, 2015). These studies suggest that CHWs' experiences require careful, nuanced consideration. More evidence is needed describing the individual perspectives of CHWs in low-resource settings, especially as relates to the benefits and demands of the role, and their competencies for managing their own self-care as well as their clients' care. Some of these considerations may be particularly relevant for women who manage households while working as CHWs. This understanding is vitally important as this cadre increasingly assumes the burden of primary health care in under-resourced communities.

The South African context is especially relevant for exploring these dynamics further. In the nearly three decades since the country's transition to democracy, government-funded CHWs have only more recently become integrated into national policies for improving quality and access to health services, through what are known as WBOTs (Schneider & Nxumalo, 2017). In response to prior shortcomings across a highly inequitable social and health landscape, however, parallel NGOs have implemented and expanded CHW programmes (le Roux et al., 2014). While this arrangement is not uncommon (Lehmann & Sanders, 2007), it also may create additional challenges for programmes and their staff operating as a supplement to formal health systems.

This paper examines the experiences of a group of CHWs navigating the crossroads between personal and professional life in an NGO-based maternal and child health home visiting programme, the Enable MM Programme, in the rural Eastern Cape Province of South Africa.

Methods

Design

This study employed a qualitative exploratory design. The Health Research Ethics Committee at Stellenbosch University granted ethical approval (N16/05/062).

The Enable Programme

Enable was established to improve maternal and infant mortality and morbidity in South Africa's O.R. Tambo District, one of the country's worst-performing health districts, located in the Eastern Cape Province (Massyn et al., 2019). Enable utilises a programme model originally developed by Philani Nutrition Centres Trust in the peri-urban settlement of Khayelitsha, South Africa (Rotheram-Borus et al., 2011). Enable, established in 2016 as the first "social franchise" of this model—taking it to a new, rural location, under new management—recruits women to work as MMs in their own communities to improve maternal and child health outcomes. Enable is operated by the One to One Children's Fund, a non-profit organisation, and throughout the course of the social franchise agreement has continued to be guided by strategic and supervisory support from the Philani Nutrition Centres Trust. While MMs work in tandem with existing governmental health infrastructure, the programme and organisation they represent are separate from the formal health system.

This model employs a 'positive deviance' approach, seeking to identify mothers who—despite sharing common adversities with their peers—practice behaviours that enable them to raise healthy children (Marsh et al., 2004). Local community leaders hold informational meetings and help programme managers identify these mothers, who are invited to submit curricula vitae. Candidates are interviewed and undergo a six-week training run by experienced trainers sent by Philani. Trainees are subsequently evaluated

through practical and paper-based examinations, and one MM per area is selected to work in the community where she resides. MMs enrol pregnant women and underweight-for-age children through home-based visits—providing education, support, and advice about nutrition, perinatal health, HIV/AIDS, and infant care, and linking these clients to necessary care (Tomlinson et al., 2016). They are expected to work 25 hours weekly (from 9:00 until 14:00) and to travel to each client's home on foot.

Study setting

The area where Enable operates consists of families living in predominantly traditional rural homesteads—which tend to be clusters of several houses and an attached enclosure for livestock, occupied by an extended family—that lack on-site running water and electricity. Approximately 89% of households served by Enable receive monthly government-issued, means-tested child support grants (nearly all households in the area are eligible). Furthermore, a large majority of adults are either unemployed, or migrate circularly or permanently to urban centres for work (Hall & Posel, 2019). Although the South African government provides free primary health care, the quality of care is uneven across a significant rural-urban divide, and is inconsistent in the O.R. Tambo District. The region has a widely-dispersed population, and resource limitations, as well as long distances to health facilities, make health-seeking challenging for Enable's clients.

Sample

At Enable's inception, fourteen MMs were selected to work in their respective areas. One MM was later promoted to the supervisory team. Each of the remaining thirteen MMs were invited, and agreed, to be interviewed by an experienced, isiXhosa-

speaking research assistant employed by Stellenbosch University (VN), with whom they were acquainted through prior external capacity-building trainings. All MMs were led through an informed consent process before the interview in their home language, isiXhosa.

Data collection procedure

CL drafted a semi-structured interview guide. The interview schedule covered topics including: working in one's own community, negotiating entry into homes, and the process of relationship-building and developing trust with clients. Questions also asked about peer support, supervisory roles, and how MMs viewed their responsibilities as lay health workers. The interview guide was revised together with VN. Three preliminary interviews were conducted in November 2017 to gather a first round of data and help refine the interview guide. From February-March 2018, the remaining ten interviews were completed; these interviews lasted between 1-2 hours.

All interviews were audio-recorded with participant consent, and each recording was securely transferred to a cloud-based platform for data storage and backup. After all interviews were completed, three experienced transcribers translated and transcribed each recording simultaneously from isiXhosa into English, discussing any challenges as a team. The interviewer (VN) checked approximately 30% of transcripts for clarity and accuracy. The senior transcriber checked those transcripts completed by two more junior transcribers.

Data analysis

The ten main interviews completed in 2018 comprised the final analytic sample; transcript data from these interviews were systematically analysed. CL read each

transcript twice and used inductive coding to identify emergent themes, resulting in 49 codes, 29 of which were present across a majority of transcripts. SR read and coded two interviews for quality control purposes (20%). CL and SR discussed key themes during multiple meetings and addressed small discrepancies in interpretation or framing. Salient themes emerging across interviews were grouped into two overarching themes—balancing roles and blurring boundaries—with seven sub-themes.

Results

MMs were, on average, 36.9 years old at the time of the interview (range 24.6-51.8 years, SD = 7.85). Six had completed high school, with the remaining four completing Grade 10 or Grade 11. At the time of the interviews, they had each been employed as MMs for approximately 18 months, and had accumulated caseloads that included an average of 30 maternal clients. One of the ten MMs had undergone health service provision training prior to being recruited by Enable.

Balancing roles: finding purpose as a paraprofessional

MMs described a sense of being recognised by the community and pride that came from their job. Leveraging their identities as community members, they stated that they connected to clients easily and felt motivated by serving their community; they also utilised professional skills to empower clients and counsel them confidentially.

A feeling of recognition and sense of dignity. MMs spoke about the sense of dignity that was a benefit of their role. They reported feeling valued, as individuals who were seen to be able to make a difference, as well as feeling pride in earning a salary and working in their own communities. One MM pointed to “*that thing of being called nurses*” as a motivator, and a way of feeling respected by the community—“*that means there is a*

big role you play” (MM6). As many residents seeking formal employment are forced to migrate and live away from their families, the ability to work within their own community was described as an added benefit and convenience. “*What is nice is that you wake up at home and go to work and you do not rent. You will bath and go to the field to people that you know*” (MM3). She continued, “*even if the money is little, that hope of having money at month-end, it can make you feel confident even when you walk on the road.*”

An ability to form connections with clients. Underpinning themes of dignity and empowerment was a deeper sense of connection. Some MMs repeated lessons from training when characterising their approaches to relationship-building, reiterating humility, respect, and approachability to gain acceptance and build clients’ self-esteem. Many approaches were tied to MMs’ embeddedness in their own communities. The idea of “being known” often reduced barriers to entry and facilitated connection; MMs often noted that their actions on the job reflected their individual characters. As one MM said, trust was essential in the job, “*especially when they know you are also from the same place, you live here, and what kind of a person you are*” (MM2). Similarly, another MM explained, “*I feel very happy because I work with people that I know most of the time, that also know me, trust me and know that I am so-and-so’s child and what my home is like because people are able to be open*” (MM7). This MM contrasted what it might look like if her interviewer were to go house-to-house, citing difficulties because clients would not know her history and might not open up with her. Another MM spoke about being the only one who graduated high school in her village, and noted, “*I never got scared [people] might judge me [as a MM]...people used to come to me because I have always been that person*”(MM5). Being ‘that person’ enabled her to feel comfortable taking on an advising, supporting role, albeit with new parameters and training.

Using context to build professional relationships. Many MMs linked their success to a specific “community member” advantage. On another level, this embeddedness also gave MMs access to insider knowledge, allowing them to use creative ways to engage potential clients—harnessing what might be considered village gossip to enrol new clients. As one MM explained:

You will hear someone saying hey sis, you must go to so-and-so's home... When I get there, I do not say, hey [this person] says that you are pregnant, no, I would just say 'I saw you girl on some other day when I was passing, and you were hanging clothes on the line, I said to myself by the look of things you must be pregnant'...they would laugh and give me the truth that I wanted, and I would open a folder. You see if I was in a village that I do not know, there is no one that would come and whisper to me about that (MM3).

Using this closer understanding of appropriate approaches, MMs described gaining their clients' trust. MMs reported that this kind of approach seemed to reduce feelings of shame or judgment of one's situation, especially as many of these clients were living in difficult circumstances. Another MM spoke about the importance of compliments:

You get in and chat in general, maybe about something that will make them happy, maybe say, “your beans look nice” or maybe compliment even the dress she is wearing...by that you are trying to build that relationship (MM2).

Choosing the right words, and being able to connect with clients in small yet important ways, was described as central to MMs' roles.

Empowering clients through the intervention. MMs spoke about empowering others as they were trained to do through home visit interactions, especially through emphasising confidentiality and autonomous decision-making. Just as closeness might foster connection, the interviewer noted that it might invite mistrust:

Interviewer: How do you [reassure] people...maybe people would say, 'no, I know [her], she grew up in this village and I would never tell her this thing because I do not want this thing to be known by people in the community'?

MM7: I would promise them that I would never talk about that thing, if they talk about it to me and to me only, they will never hear another person talk about it...I was taught a lot about that.

Echoing this theme of client respect, MMs explained the importance of a client making decisions about her own health: *"I do not force the person. Everything is up to her"* (MM7).

Another emphasised:

I don't wear my client's shoes...all I do is I give advice to my client about that situation she is facing at that moment so, I sit down with her and talk about how what I think about that situation, but I don't make decisions for her and also ask her what she thinks (MM10).

This approach reflected a delicate balance between engaging the personal with the professional, prioritising a client's right to privacy within a tight-knit community, alongside a right to autonomy.

Blurring boundaries: encountering challenges in the job

As MMs emphasised their ways of capitalising on their community embeddedness, they also acknowledged the ways that it might demand more of their professional and personal selves. Being recognised also meant bearing the weight of expectation; MMs had to navigate both sides of this role, with less control over where boundaries might be drawn.

"No one asked me [to do this]." MMs spoke about being available for their clients at all times—even when this conflicted with their personal lives or professional training. For many MMs, having to restrict their working hours to between 9:00 and

14:00 was unrealistic if clients had additional needs. One MM described “leaving the pots on” after she had started making dinner to put on her uniform and go help a client who had called with an emergency. She noted:

You don't ever think that you supposed to tell the manager that today, I left work at five, the only thing you think is that I have to help this person, [it] doesn't matter what time I knock off, I'm not supposed to say I'm rushing for 14:00, rather this person die because you want to knock off at 14:00 (MM6).

She noted this was part of the job for which she was grateful: “*if I pushed and managed to help a person, I see that as an achievement even though it was difficult.*” Often, MMs did not seek credit or pay for this additional work, recognising it as essential for the client but something they were not necessarily supposed to be doing. While MMs described this practice as fulfilling their responsibilities to their clients, they simultaneously blurred the lines of what might be seen as professional.

Most MMs portrayed these tendencies to help after hours as self-prompted, rather than based on their proximity, on community members' expectations, or a sense of guilt. Some MMs discussed the need to apply principles of fairness across clients, especially in challenging cases:

[Later] I would be thinking of a plan to use in order for things to get better there...Because of the way that I am so eager to make a change in the community, so that thing makes me feel guilt, it would seem like I am not attending their problem because of a reason (MM4).

This sense of commitment often embodied more instrumental forms of support. MMs spoke about bringing food from their own gardens to certain clients so that they could digest their antiretroviral medication, and sending sick children to the clinic on public transport using their own funds—yet described these acts as routine. Even if this extra effort sometimes felt like a burden, MMs seemed willing to shoulder that

responsibility: as one MM explained, *“I would say, I made myself tired, because no one asked me [to do this]”* (MM1).

This ambivalence between choice and constraint also related to how situations could be reflected back to the MM. One MM noted that being close to clients also invited the possibility that any gossip about someone’s health information could be pinned back on the MM, even if she was not to blame (MM3). Others described an internalised imperative to “live” the role, reiterating: *“I must do what I tell people to do. They must see me doing it”* (MM1). For many of the MMs, testing for HIV and being open about their status was one example of this, especially in a region with high prevalence rates but similarly high stigma. One MM spoke about how she used to run an informal tavern, and she realised she had to choose between being a MM or keeping her business open to reflect her own integrity. Using personal examples with their clients, MMs reiterated the importance of taking their own advice, revealing reverence for, and perhaps bounds set by, the role they had taken on.

Struggling to practice self-care. While most MMs recognised the need for self-care to do their jobs well, some MMs struggled to keep home and work separate. One MM described her after-work routine: *“we were taught that we must not take people’s things and make them ours, so I would get home, drink water and be at peace”* (MM8). Another noted, *“[you can] lose your situation over problems that are not yours”* (MM9) if you start to reflect on clients’ problems. By not promising clients more than they could give, MMs found ways to erect boundaries:

We do not promise things that we do not have, we tell them that we bring nothing, we just came in to change the situations in homes, with things like, what must one do when they are pregnant, what must they do with the baby is underweight, there is nothing else that we bring (MM10).

In these ways, MMs articulated their capacities to make distinctions between clients' problems and their own lives, especially where they were experiencing similar deprivation.

Nevertheless, some MMs struggled to manage these burdens, particularly those who described being emotionally connected to clients. One MM described coming home to rest after difficult days and having to explain her tiredness to her daughter:

At home they now know, I just go to sleep when there is something troubling me. My daughter would ask me, 'mom, what happened in the field? why do you come home troubled?' I would tell her that, 'no, stop, I just need to sleep first,' I would then sleep. When I wake up, [I] tell them that it is because we work with people and sometimes the problems would be too much in the community, so sometimes you must just leave me (MM4).

Often, problems might re-emerge after the working day had ended, and unresolved issues could weigh on MMs' consciences as they cooked dinner, engaged with their families, or lay awake at night.

MM7: You have a big challenge every time you arrive [home] and your mind is still on that thing, even though sister said in the training that you must not carry someone's burden. But it is not easy to not carry that person's burden, because you want to help that person, sometimes you would feel that there are difficulties.

Interviewer: Okay...what do you think it is that causes that?

MM7: I think that it is caused...I would say, sis, it is caring, caring for that person, you wish to see them past that problem.

Despite professing an understanding of self-care and boundary-setting, the blurring of boundaries and closeness to clients in practice complicated this logic.

Disrupting dynamics at home. Lastly, even as MMs discussed being able to empower clients to seek care and make decisions, they sometimes encountered resistance to their own empowerment as MMs in their personal lives. Being an employed person in a community with extremely low rates of formal employment engendered a different burden, inviting accompanying jealousy from this status change.

People are alright now, but when we started, yoh, it was hard because we were many when we went to the training, and we were not all hired. So when you enter a home you would have to explain why so-and-so was not hired and why were you hired, and you don't even know why you were hired at that time (MM8).

In addition to facing scrutiny from community members, some MMs described a disrupted home dynamic due to shifts in cultural expectations. One of the MMs who was married spoke about her newfound financial independence as something that her husband both appreciated, and felt threatened by.

MM7: He would feel like that, when he was not working he was happy that I was working, but he was worried that he was supported by his wife at the end of the day.

Interviewer: What are the things that he would say, or express himself with, to show that he does not like being supported by his wife?

MM7: For example, my husband is someone that drinks, he would come home drunk and say, 'hey, this thing of being supported by a wife, having your children raised by the wife, with food I am looking at this wife, with everything, even at school she has to take care of the children.' He would look down on himself, you see?

As this MM articulated some of the tensions that had entered her marriage and home, she was simultaneously able to recognise these challenges and contextualise them. Another MM shared tensions that had arisen in her household, where she as a young wife (*makoti*) was expected to plan meals and clean. After accompanying a client to an

emergency clinic visit, she recalled, “*I arrived at home past eight and when I got home, I saw the mood had changed, but I told myself that what matters is I helped the baby*” (MM6). Despite the apparent irritation from other female household members, she said her husband and family had come to acknowledge and accept her new role.

Discussion

In this article, we have described the complexity MMs face—as women trained and employed to deliver a maternal and child health intervention in their own communities—in navigating the crossroads between their professional roles and their personal lives. This process of engaging in a relatively new role within a familiar context was described by many as empowering, pushing them to “live” their role with a deep sense of personal integrity. In bridging personal and professional domains, MMs identified ways of forging personal connections while also using their professional role to establish credibility. They drew strength from being recognised and respected in their communities and internalised the importance of their roles as they described working extra hours and being available for clients. In other literature, CHWs often self-identify as advocates and connectors, employing flexibility and creativity to meet their clients’ needs (Ingram et al., 2012).

However, this role also exposed them to community and familial expectations: of selflessness, equitably-applied care, maintaining domestic responsibilities at home, and a tacit understanding that extra work did not amount to extra pay. As such, the advantages they experienced were also tempered by conflicting situations they faced. Not all challenges described were specific to community health work: they included finding a balance between home and work spheres, adapting new strategies to reach job-related goals, and employing personal qualities and acquired skills to perform well (Buykx et al.,

2010). However, other experiences echoed the burdens facing other South African health personnel in rural settings (Braathen et al., 2013; Engelbrecht et al., 2008), and also reiterated the distinct challenges that CHWs navigate (Razee et al., 2012; Roman et al., 1999; Scott et al., 2018). As CHWs' work and home spheres overlap more than usual, they may face expectations (or create them) about when boundary-setting is acceptable, and when it is not. For example, feeling obligated out of a sense of loyalty or care to provide a hot meal, or a transport fare, to a struggling client was not atypical; yet it posed challenges for MMs who were not necessarily always in a financial position to provide this mode of support.

While recognising the value that individual MMs place on their roles, it is also necessary to think critically about what these challenges mean for CHWs, who are often pitched as a “solution” workforce for countries struggling to meet population health needs (Colvin & Swartz, 2015). The substantial public health literature on CHWs in LMICs, and the daily challenges they face, tends to focus on performance improvement—citing barriers around community acceptance, equipment needs, and training needs more specifically (Ballard & Montgomery, 2017). Fewer studies investigate the role of occupational, CHW-specific challenges of working within their own communities (Trafford et al., 2017). For the MMs in this study, employed by a non-profit organisation to expand care to maternal and child clients in areas far from health facilities, these roles may be even more community-centric when compared to South African government-funded CHWs who are primarily based in clinics and are expected to conduct outreach work (Schneider et al., 2018). These considerations are also largely absent from larger-scale research and advocacy work that advocates task-shifting key health roles to CHWs (World Health Organization, 2018a). The advantages of CHWs, such as their comparably low cost (McCord et al., 2013), cultural affinity with clients

(Kok, Ormel, et al., 2017) and logistical flexibility as a workforce (Herman, 2011), are often posited as critical determining factors in national strategic plans and global guidelines promoting CHWs—at the expense of more personalised, nuanced examinations of their experiences and capabilities. Our research attempts to address this gap, and we consider three potential “levels” to consider how to interpret and operationalise these findings in other community health programme contexts. We believe these implications are relevant for both NGO-based community programmes such as Enable, as well as nationally-implemented programmes.

Implications of these findings: immediate, intermediate, and conceptual

At the most immediate level, these findings highlight a need for programme leadership to equip CHWs with self-care and boundary-setting skills. Pre-service and in-service training should be framed to equip CHWs with opportunities for growth and skill-building, and should consider integrating this skillset with sessions on soft skills such as interpersonal engagement or relationship-building. These skills can include evidence-based techniques for self-care and stress relief—identifying stressors, journaling, support networking, and/or relaxation techniques. They may also harness locally-derived strategies that CHWs are already effectively employing in their daily work. Just as some MMs shared strategies to detach from their clients’ needs when arriving home, other research has echoed the need for health workers to engage in client relationships without becoming too invested. Accredited Social Health Activists (ASHAs) in India performed better and were found to be better protected against stress and burnout, when they practiced “surface-level” emotional labour that enabled them to connect to clients outwardly. ASHAs engaging in “deep-level” emotional labour, conversely, took on more clients’ burdens and suffered from this closeness (Pandey & Singh, 2015). Similar

research with Brazilian community-based health agents and South African community-based volunteer caregivers has also identified high levels of stress and burnout, stemming from lack of support, depersonalisation, and emotional exhaustion (Akintola et al., 2013; Silva & Menezes, 2008). However, additional work from LMICs is needed in order to frame successful strategies for mitigating these factors and better supporting staff to erect necessary boundaries.

Secondly, many CHW models would benefit from more routine opportunities for supportive supervision to reduce occupational burdens. Programme leadership should carefully consider these provisions at the inception stages of programme implementation and at any subsequent stage of expansion. While MMs shared their personal ways of coping, they spoke less about routine, structured opportunities for sharing emotional burdens with peers and supervisors. Supportive supervision, which extends beyond managerial oversight to encompass a more multi-faceted “humanised” type of support, has been found to be linked with improved CHW performance and motivation (Kok et al., 2018). Such comprehensive supervision can be challenging to implement consistently, however, facing the same geographic and resource limitations that programmes themselves encounter (Bailey et al., 2016; Ndimba et al., 2015). Additional psychosocial support strategies – such as routine debriefing, a strategy commonly used with registered counsellors and mental health professionals, as well as peer-to-peer support—could further benefit and support CHWs (Deahl, 2000). Shifting the supervisory focus from observing clinical challenges, monitoring performance, and providing informal support (Hernández et al., 2014) to providing structured opportunities for debriefing, case sharing, and team problem-solving (Rabin et al., 2000; Tseng et al., 2019) is an important step in constructing a more supportive, responsive programme. There is further scope for research on supervisory mechanisms and practices

to understand how to mitigate challenges within community settings and ensure quality in programme implementation (Rotheram-Borus et al., 2017).

On a broader conceptual level, these findings also highlight ways that existing models and assumptions about CHWs may disadvantage these workers. Lay and community health workers are overwhelmingly women, seen to fit nurturing roles as “care workers”, who tend to be remunerated poorly, if at all (Daniels et al., 2012; George, 2008). CHWs are often seen as an indispensable solution to health system failings from policymakers’ perspectives, able to operate within “lean” models of care and mobilise in the face of considerable resource constraints. On the other hand, they take up the mantle of work that a functioning health system should be conducting, and do so in ways that are often undervalued and overlooked (Di Paola & Vale, 2019). How can CHW models be strengthened to fit these needs and plays supporting roles, without placing undue burdens on CHWs?

One response is a clearer division between personal and professional domains, comprising a more intensive, up-front investment in training and professionalising the CHW workforce. This approach moves beyond the “positive deviance” model, which has been found to be a promising way to identify motivated, gifted CHWs, but may also blur the boundaries between personal and professional to create a greater burden. By living and working within the same community, CHWs may engage more intensively with beneficiaries than formal health sector interventions could (Smith et al., 2014). However, there are ways to establish divisions more concretely. Training CHWs on how to provide “synthetic social support”—characterised by targeted (not organic) social networks, and non-reciprocal, time-limited client interactions—is one such approach to creating these boundaries from a programmatic perspective (Gale et al., 2018). This approach might also entail more centralised, standardised recruitment criteria and

training curricula, and higher standards of accountability in care. For example, in Kazakhstan, all pregnant women and families with children under age 5 are visited at home by patronage nurses and social workers as part of a universal progressive model for primary care (Sukhanberdiyev & Tikhonova, 2019). This approach represents a cross-sectoral, sustainable effort; community health teams have begun to undergo comprehensive training, and training modules have been incorporated into medical and nursing curricula to ensure widespread uptake and impact.

A second response is to provide CHWs with a clearer path to professional development, as a similar way to embed CHWs within the larger health workforce. As CHWs implement interventions on the front lines, they face decisions about how to flexibly adapt strategies to meet unanticipated community needs or adjust to contextual changes (Ingram et al., 2012). From a practical perspective, understanding CHWs' personal goals and prioritising opportunities for professional development can help promote their growth and longevity both individually and collectively (Abdel-All et al., 2019; Pallas et al., 2013). It also positions CHWs to develop within and beyond their roles, as evidence shows that many CHWs use the role as a stepping stone to further career opportunities (Lloyd & Thomas-Henkel, 2017; Schneider et al., 2008; World Health Organization, 2018a).

Both of these approaches involve a clearer, more defined role, and would also require adequate pay and resources for CHWs to operate at a high level. These suggestions, however, may also inherently lead into a sort of tension surrounding the definition of CHWs' roles, as too "professional" a framing may distance them from the very communities and individuals with whom they aim to connect and serve. Consequently, CHW models must continue to work alongside clients to establish appropriate expectations from an early stage, and ensure that both CHWs and clients

feel supported and respected. Importantly, these recommendations extend to diverse types of CHW workforces. WBOTs, the most recent iteration of South African policies promoting government-employed CHWs, have been implemented slowly and unevenly, yet would similarly benefit from incorporating support and role definition for CHWs as they continue to be rolled out (Schneider et al., 2018).

In addition to considering practical responses to challenges inherent within CHW models, a more fundamental rights-based framing is needed (Trafford et al., 2017). As CHWs are embedded within complex environments and larger systems, their motivations and experiences are multi-dimensional and diverse (Swartz, 2013). While continuing to incorporate local community networks and knowledge is critical, shifting towards a more professionalised community health system would also acknowledge the pivotal, preventative roles played by CHWs, and could allocate resources for them to effectively serve vulnerable communities.

Limitations

This study has a number of limitations. All interviews were conducted with the first cohort of MMs from the Enable Programme, who were recruited to establish the programme in Nyandeni and therefore may have experienced the added burdens of reflecting the programme's values and goals in their daily work. This challenge may have been somewhat diminished for later cohorts of MMs who joined after the programme was well-established in the area. Furthermore, the interviewer (VN) was known to the participants previously, through her visits as an external trainer from Stellenbosch University. While we believe this prior contact was an overall advantage, it is possible that certain participants withheld certain perspectives or information with the understanding that it might be shared with their supervisors. However, we are confident

that the informed consent process and existing relationships acted as protective factors against this limitation.

Conclusions

Our findings add to ongoing dialogue about how to sustain and expand CHW programmes to reduce the burden of health for LMICs. Interview data from CHWs highlight the conflicting nature of their roles, and the tangible challenges that they face in working in their own communities. We emphasise the need to reconsider the assumptions that underpin community health programmes and suggest responses that might help elevate and professionalise these individuals. Future research on CHW performance, and implementation research focused on evaluating and expanding CHW programmes, should incorporate a more nuanced understanding of CHWs' diverse roles and the ways in which they navigate their own lives and identities in the context of their work.

References

The references for this article can be found integrated into the final References section of this dissertation, beginning on page 169.

Chapter 6: How do pregnant women and new mothers navigate and respond to challenges in accessing health care? Perspectives from rural South Africa

Introducing Article 4

This is the final of four articles that comprise this dissertation. Using the same 26 client interviews as in Chapter 4, I explored experiences of clients outside the realm of the Enable Programme, as they sought health care services from formal health facilities. Clients described their responses to interpersonal and structural barriers to care: strategies ranging from adopting patient, accepting attitudes, and enduring long waiting times and miscommunication in the hope of being treated, to taking more active measures to protect against disappointment, rely on support networks, and assert themselves in health care facilities. This article brings to light an emergent reality—that programmes cannot and should not be seen as a solution to high demand and overburdened systems. This work also represents an opportunity to share and reflect on the strategies that rural women are employing constantly, to navigate barriers and to preserve a sense of dignity in a de-personalised and highly inequitable system of care.

This article has been published in *Social Science & Medicine*. It is reproduced as an in-text chapter in this dissertation, in the same style as it was submitted for publication. It is available in its published article format in Appendix B on p. 233, and can also be found at the following reference:

Laurenzi, C. A., Skeen, S., Coetzee, B. J., Gordon, S., Notholi, V., & Tomlinson, M.

(2020). How do pregnant women and new mothers navigate and respond to challenges in accessing health care? Perspectives from rural South Africa. *Social Science & Medicine*, 258, 113100. <https://doi.org/10.1016/j.socscimed.2020.113100>

Abstract

Women in LMICs and in contexts characterised by inequality face various interpersonal and structural barriers when accessing formal maternal and child health (MCH) services. These barriers persist even in contexts where programmes to increase access to services, such as CHW interventions, have been implemented. However, while barriers to accessing care have been extensively documented, less is known about the diverse ways that women respond to, and navigate, these situations. This study explores strategies pregnant women and new mothers use to navigate and respond to health care barriers in a rural district in the Eastern Cape, South Africa. Twenty-six pregnant or recently delivered clients of the Enable MM programme were interviewed about their experiences of accessing formal MCH services. Interviews were conducted between February-March 2018 by an experienced isiXhosa-speaking research assistant, translated and transcribed into English, with transcripts coded and organised by themes using ATLAS.ti software. Facing resource shortages, inconsistent communication, and long travel times to clinics, participants employed diverse, innovative strategies to navigate interpersonal and structural barriers to care. While some participants chose to respond to barriers more passively—citing endurance and acceptance as practices of health system engagement—those participants who focused more on active responses tended to leverage their education, existing relationships, and available community resources to overcome barriers. Nevertheless, most participants described feelings of frustration and dejection. While CHW interventions may alleviate some of the burdens facing fragile health care systems in these contexts, these programmes still rely on an underlying infrastructure of care that primary health care clinics and hospitals should be providing. Future programming should work in tandem with formal health systems and should

support staff to improve quality of care provided to pregnant women, new mothers, and their infants to prioritise their health at a time of vulnerability.

Introduction

The perinatal period is a time of vulnerability for women and their infants that requires comprehensive, attentive health care to protect against risks to maternal and infant morbidity and mortality (Graham et al., 2016). Maternal and infant wellbeing is as much an individual as it is a societal imperative; the ability to seek and receive adequate health care during this life stage is central to promoting healthy development and enabling women and their families to flourish (Stenberg et al., 2014). Recently, global priorities have aligned to advocate for mothers and children during this critical time; the Nurturing Care Framework (World Health Organization, 2018c), Sustainable Development Goals (Le Blanc, 2015), and drive for Universal Health Care (Ji & Chen, 2016) all contain provisions for improving outcomes for maternal and neonatal populations, especially in low-income settings. However, the poorest, most marginalised women often have negative experiences accessing health services, with health inequities impeding access to quality care (Finlayson & Downe, 2013).

Pregnant women and new mothers in LMICs face significant barriers to accessing care, in both individual and structural domains, and may struggle to respond to these barriers in effective ways (Guliani et al., 2013; Langlois et al., 2015). On an individual level, health education and influences of social and family networks may drive how, when, and with what frequency pregnant women seek care (Binder-Finnema et al., 2015; Kifle et al., 2017; Munguambe et al., 2016; Scheffler et al., 2015). Interpersonal interactions also shape individual experiences of care, for example, how women are regarded and treated by health providers. A systematic review of interactions with

maternal health care providers in LMICs, including doctors and nurses, found that negative attitudes and experiences outweighed positive ones and adversely affected patients' wellbeing and willingness to seek care (Mannava et al., 2015). Structural factors, such as infrastructure, transport affordability and availability, sufficient resources and medical supplies, and household vulnerability can also determine whether women are able to access care, and what these experiences are like (Abrahams et al., 2001; Puett et al., 2015). Women have highlighted the importance of structural factors in shaping their satisfaction with MCH care (Srivastava et al., 2015).

For pregnant women and new mothers living in remote, rural settings, these challenges can be heightened. At an interpersonal level, the quality of care received at rural health facilities may be poor. Rural health providers have reported demotivation, dissatisfaction with rural postings, and high stress about resource limitations—resulting at times in what they acknowledge as poor treatment of patients (Melberg et al., 2016; Prytherch et al., 2013; Thi Hoai Thu et al., 2015). From patients' perspectives, a lack of mutual trust and experiences of mistreatment and abuse during health visits, including delivery, create a similar sense of dissatisfaction with services and reduce motivation to seek care, especially amongst the most vulnerable women (Adatawa et al., 2019; Bohren et al., 2019). Structural challenges also persist. A study in rural Ghana highlighted difficulties that women faced in obtaining vehicular transport for MCH care, in large part due to location and poor road networks, leading them to opt for less safe transport or care options (Atuoye et al., 2015). In Liberia, increases in distance from a health care facility were found to have a direct, negative relationship with uptake of MCH care-seeking, predicting varying levels of engagement by rurally-based women (Kenny et al., 2015).

Responding to barriers to care

While these diverse challenges to seeking and receiving maternal health care have been well documented across LMIC settings, knowledge about responses to these barriers is limited. Some community-based efforts, such as women's groups, have shown promise in building capacity and sharing information (Morrison et al., 2010), and pairing savings initiatives with health education and social support (Shaikh et al., 2017).

Community loan funds to facilitate maternity transport have also been found to have positive effects on facility-based deliveries, emergency access to care, and general uptake of health services (Ekirapa-Kiracho et al., 2017; Nwolise et al., 2014). On a more widespread scale, CHW programmes may be able to improve linkages to care through educating and empowering clients and establishing communication channels and referrals systems (Lewin et al., 2010).

However, there is less evidence on how women individually navigate these complex multi-level barriers to accessing health care, at both interpersonal and structural levels. In settings where gender roles are clearly defined, or where men are working away from their homes, women alone may bear a greater responsibility for childcare, which includes accessing health services during pregnancy and following birth (Bougangue & Ling, 2017). The individual perspectives of these women can provide important insights into how pregnant women and new mothers experience the process of accessing care, and how their right to health care is being met or prevented. The strategies and solutions that these women devise can also provide a foundation for how government and other service providers tailor their care and craft appropriate responses (Kornelsen & Grzybowski, 2006). While many women face constraints related to poverty and marginalisation, they employ diverse responses to health care barriers.

This study presents findings from the rural Eastern Cape in South Africa about how pregnant women and new mothers navigate and respond to challenges in accessing health care during the perinatal period.

Methods

This study employs a qualitative research method, and was part of a larger study evaluating the Enable MM Programme aimed at improving maternal and child health and nutritional outcomes amongst vulnerable households. Ethical approval was granted by Stellenbosch University's Health Research Ethics Committee (N16/05/062).

The Enable MM model

The One to One Children's Fund established the Enable MM Programme in 2016 as the first "social franchise" of the Philani MM home visiting model (further referred to as Philani). Philani first launched its programme to address maternal and infant mortality and malnutrition in a peri-urban area outside Cape Town in the early 2000s. Enable's "social franchise" transported this model to a new rural area, under new management, with continued support from Philani (Laurenzi et al., 2019; Rotheram-Borus et al., 2011). Enable's MM model looks for women who may be "positive peer deviants"—caregivers who have managed to raise healthy children despite adverse circumstances. Potential MMs are identified by traditional or other community leaders, as well as through advertisements. After submitting curricula vitae, a subset of applicants are selected to participate in a six-week training with experienced trainers. Training includes content on building client relationships, antenatal and postnatal care and nutrition, infant care and nutrition, HIV/AIDS, and social support. Trainees are invited to become MMs based on their geographic location, and if they successfully pass a

written examination at the end of training. MMs work in their own communities, identifying and enrolling pregnant women and malnourished children, and deliver health education, support, and referral services to clients in their homes. Fourteen MMs were recruited into Enable's first cohort in 2016, and one subsequently was promoted to a supervisory role, leaving 13 MMs working in the original programme areas.

Setting

Enable's MM Programme operates in a remote and rural part of Nyandeni Municipality (population 290,320) in South Africa's Eastern Cape Province (estimated population 6.5 million) (Statistics South Africa, 2011, 2018). While South Africa's health system is characterised by stark differences in access and quality, the former "homeland" areas of the Eastern Cape have particularly poor health care outcomes. Nyandeni is situated within one of these areas, in the O.R. Tambo district, which has a maternal mortality rate well above the national rate (196.9 deaths per 100,000 live births, compared to the national 116.9) (Le Roux et al., 2015; Massyn et al., 2017). The O.R. Tambo was among the top 10 districts with the highest proportion of facilities reporting a medicinal stockout in 2017 (StopStockouts, 2017). Nyandeni Municipality has the lowest district-wide rates of early antenatal visit booking, with more than a third of pregnant women not completing antenatal visit before 20 weeks (Massyn et al., 2017). However, its inpatient early neonatal death rates are also well below the national average.

Recruitment

Participants were pregnant women or new mothers who had been enrolled in the Enable MM Programme and were clients of one of Enable's 13 MMs. To ensure a variety of different perspectives on the programme and allow for geographic variation,

an equal number of clients per MM (n=2) were purposively sampled from each MM's caseload, which contained, on average, 30-35 maternal cases. The first author (CL) also checked that client characteristics varied by age and number of prior children. In cases where a potential participant was unreachable by phone, unavailable, or uninterested in participating, a backup participant sharing the same MM was contacted instead. A number of clients initially contacted were temporarily working away from home (n=3), were uninterested (n=1), or were unreachable by the interviewer (n=8) due to mobile network issues or a change to their contact number, requiring a backup participant to be contacted instead to reach the intended number of clients.

Data collection tools and procedures

Interviews were conducted from February-March 2018 by an isiXhosa-speaking research assistant (VN) with extensive experience conducting qualitative interviews. Interviews were guided by a semi-structured interview schedule. CL and VN met to discuss each question on the interview schedule to eliminate instances of ambiguity and revise the schedule for simplicity and clarity. The interviewer contacted potential participants, scheduled interview times, and visited each participant to conduct the interview in her home. The interviewer obtained written informed consent from all of the participants. Further, all of the interviews were conducted in participants' first language, isiXhosa. Throughout the two-month interview period, CL and VN discussed progress 3-4 times weekly, including individual interview highlights and challenges. Interviews were audio-recorded with permission from the participants. Interviews were, on average, one hour each, with most interviews falling between 45 and 90 minutes' duration.

Transcription and translation

Interviews were transcribed verbatim and translated from isiXhosa into English. Transcription took place between April-October 2018. Two experienced isiXhosa-speaking transcribers listened to the audio recordings of the interviews, and transcribed the interview content using MS Word, translating directly into English. In some cases, specific words were left in isiXhosa to preserve their meaning (for example, traditional Xhosa beliefs/concepts about pregnancy). Alternative definitions were given as appropriate. A senior isiXhosa-speaking member of staff quality checked 50% of the transcripts for accuracy and determined them to be of high quality.

Ethical considerations

During informed consent procedures, the interviewer ensured that privacy and confidentiality were discussed, and that participants understood how their information would be used and were given the opportunity to ask questions. All consent forms were anonymised using a unique participant identifier, and this identifier was also used to label audio recordings, transcriptions, and data analysis files. The audio recordings were removed from the recording devices at the end of each day; they were first stored on a password-protected laptop in a locked room at the research site in Mankosi, filed by date completed and participant identifier, and later transferred to a cloud-based folder. This folder was used to securely transfer and complete the transcription and translation processes. Referral mechanisms were established in case of participant distress or additional challenges identified by the interviewer, but did not have to be utilised during the course of fieldwork.

Data analysis

Data were coded and organised using ATLAS.ti qualitative software. All transcripts were read and coded with a specific focus on data related to experiences of accessing health care, challenges in accessing care, and responses to these challenges, using an inductive coding method. While participants were interviewed as part of a larger study to explore their engagement with and perceptions of the Enable Programme, their experiences of accessing health care emerged as important aspects of these interviews. From an initial list of 98 codes inductively generated from the full participant interviews, 14 codes specifically related to accessing health care. Interviews were re-read with a closer focus on this particular aspect of the data, and an additional 14 codes were identified; thus, 28 relevant codes were ultimately identified regarding these experiences, challenges, and responses. This final code list was shared with a second coder (SG), who read and coded three transcripts. Double-coded transcripts were compared to ensure consistency. Themes and sub-themes, discussed with co-authors, were generated from grouping similar types of barriers and responses together.

Results

A total of 26 participants were interviewed between February and March 2018, representing two clients per MM. Participants' mean age was 26.9 years (SD=5.77), eight were married (30.8%), and 10 were first-time mothers (38.5%). 57.7% of participants had been enrolled in the Enable Programme during its first six months operating in Nyandeni (July-December 2016). The 28 codes identified in the interview transcripts were grouped into 2 themes and 4 sub-themes (Table 7). The majority of participants described accessing health care at one of two government clinics in the local area.

Table 7: Themes from client interviews

Responding to interpersonal barriers to care
Passivity and acceptance in interpersonal interactions with health care staff
Navigating interpersonal interactions more assertively
Responding to structural barriers to care
Frustration and hurt from repeated systemic failings
Troubleshooting and planning ahead

Responding to interpersonal barriers to care

Discussing interpersonal interactions in clinic settings, predominantly with facility staff, participants described a lack of communication that they had come to expect, and accept, as well as poor quality care tied to resource shortages and inconsistent procedures at clinics.

Passivity and acceptance in interpersonal interactions with health care staff.

Participants were mindful of tacit patient-provider hierarchies as they spoke about adopting passive strategies to maximise their chances of being treated in a timely way, or at all.

Participant Identifier (PID) 2: I keep quiet...

Interviewer: Mmm, are you afraid?

PID2: No, I'm not afraid, but I just want them to help me...Because if I can express myself,

I might go back [home] hurt...I have to wait.

She later continued:

If you go there, you must be calm and relax, because you would feel like they are not paying attention to you because you are so many, others came for their own problems...then you don't have to rush them, you must wait for them.

Returning home “hurt,” at not having been treated at all, was something that other participants raised concerns about. To some women, acceptance or “endurance” was part of the process of receiving care:

They do shout at us, but since we are women we endure, just if she is shouting at you but doing it for you (PID21).

While participants articulated the challenges and mistreatment they encountered, and the consistent frustrations experienced during clinic visits, they also chose to defer to health care providers and wait their turn.

Some participants adopted a more accepting approach to barriers to care, sharing various reasons for this decision. Often, they attributed poor interpersonal engagement from health staff to larger health systems issues that those staff faced. Participants said they fully expected clinic visits to be a daylong commitment, and some explicitly lamented “*there is nothing you can do*” (PID11). Most participants’ days began with time-intensive travel to the clinic, “*then when you get there, you sit for long and be told to wait, wait, and wait, you will be waiting for long*” (PID20). Some participants accepted the limitations facing their clinics and staff, sharing a degree of sympathy once these challenges were communicated to them. Noting that clinics tend to be out of stock on a regular basis, one participant noted:

PID25: They say...but, shame, they do explain to us, they say that they order treatment while they still have [it] in stock and then it would delay, a day or 2 weeks or 3 weeks without it.

In other cases, health providers were less communicative and less systematic. Another participant described how nurses operating alone often had to choose one group to start with:

Maybe a nurse may come, for example the one that works with children. She weighs, she immunises and does antenatal care all alone, then maybe the nurse would say “no I’m going to start with those who are pregnant, new mothers must wait” or say “I’m going to start with new mothers.” Clinic procedure does not depend on time, it does not matter even if you woke up in the morning or not (PID3).

The act of showing up at the clinic did not guarantee that an individual would receive care; participants mentioned that this was often left to chance, or just “how things work,” and indicated that there was limited action they could take to change this situation.

Navigating interpersonal interactions more assertively.

Empowerment and education as important tools. Other participants adopted responses that were more direct, electing to resist or make their voices heard, and spoke about the impact of education and awareness of their rights. A young mother who spoke of nurse mistreatment shared:

They [nurses] have that belief of they can treat people in any way, the way she likes.... You would find out that some people are not able to oppose what they are saying. So when I grew up, I realised that I cannot tolerate that (PID11).

This approach was not common for most participants, and this particular woman cited her higher education and self-confidence as playing a role in advocating for her own health needs. Other experiences illustrated participants’ sense of empowerment in clinic-based interactions based on routine home visits with their MMs.

PID18: The difference is, sometimes when they are telling me something at the clinic, they tell me things that I know already [from my Mentor Mother]...

Interviewer: Okay, so you go there already with your information?

PID18: Yes.

To some, having the additional support of a MM became a way to better understand the information given to them at clinic, and also equipped them with information that they might use to question and engage health workers. This participant spoke about complaining to a nurse about being overlooked, and noted: “*Obviously, it can’t be not heard when you are angry*” (PID18). Participants’ communication strategies also included drawing attention to urgent health needs, especially in cases when the health facility staff was taking a break:

You must shout if your child is not okay...up to a point [where] even someone who is passing by the road can hear (PID1).

Drawing on their own education and tested strategies, as well as on additional MM support, participants described assertive strategies for being helped.

Special relationships as a means to receiving care. Other participants indicated that the best way to access care was through being “*known by*” (PID18), or “*hand in hand*” with a nurse (PID2). Seeing a system that did not serve its patients equally or with care, these participants stated that existing personal relationships with clinic staff sometimes worked in patients’ favour, having experienced this personally or observed it with other patients. Additionally, as clients of the Enable Programme, some participants described the tangible impact of having a MM to facilitate referrals for special cases. One participant said, of her MM, “*you cannot end up dying in her presence*” (PID2), indicating that having a MM meant having access to necessary care and attention regarding important health needs. Having a referral in-hand often meant readier access to care for participants.

Interviewer: When [your MM] writes you this letter, does it help you when you go to the clinic? For example, the nurses—are they not saying, “where did you get this letter?” and so on and so forth?

PID12: No, they would look at it and ask which Mentor Mother gave me this...who gave me this, and I would tell them I got it from my Mentor Mother called [MM name], then it would be signed, then they would ask me about the pains I am feeling.

The additional support and treatment that participants cited—whether through nurse familiarity with Enable, or through personal connections—conferred a sense of empowerment, enabling them to access further channels for recourse when facing routine health barriers.

Responding to structural barriers to care

In addition to sharing interpersonal challenges during clinic visits, participants described substantial barriers to receiving quality care related to structural shortcomings.

Frustration and disappointment from repeated systemic failings. Many participants shared feelings of disappointment, as well as diminished motivation to seek health care, after not receiving adequate services. Structural barriers, such as two-hour trips on foot to the nearest clinic, compounded these systemic failings. Speaking about medicinal stockouts, a participant labeled these regular occurrences as displaying “carelessness from the government,” asking, “they know the life of that person depends on that treatment, so how can they not have treatment?” (PID25). These responses were exacerbated when participants took initiative by keeping track of required immunisation dates, or had an ill child needing medicine, and were not sure whether or when they would be able to afford a second trip (PID17).

You just feel disappointed, having no interest to get back there again, because even that time you will be going there to check, not knowing if [immunisations] are available (PID6).

Participants also spoke about feeling unrewarded for their efforts such as taking a day off work to attend clinic for her child's immunisations:

When I decided to go on that day, I would have told myself that day is for the clinic...maybe I would be busy on the day they say I must go [return again], it is worse [harder] that I am here [working] at the creche now, I would have asked permission for that certain day (PID7).

Participants also conveyed how these experiences restricted their choices, or their ability to act in their own or their child's best interests. While stockouts were common reasons for not receiving needed care, participants who required more comprehensive clinical care also struggled to move between facilities because of lack of funds:

I do not want to lie, it was when I was still pregnant, I was in pain, I went to the clinic and when I got there, they wrote me a letter to go to [the hospital] and I did not have money to go...I came back home sister, I did not go because I was borrowing money and I was not getting [earning] money and there is no other way because from here to [the hospital], it is R20. So I couldn't, sister, because of that (PID10).

Another participant spoke about “*just losing power*” from repeatedly frustrating experiences, which made her less inclined to attend the next given date; she explained that she might, in response, take her time and “*go there on my own date that came to my mind*” (PID21). Some participants relayed stories—their own or their neighbors’—when they did finally attend clinic after a scheduled visit and were summarily reprimanded for their tardiness.

Troubleshooting and planning ahead. While many participants took stockouts and onwards referrals personally, there were other participants who sought to

circumvent structural challenges in other ways. They adopted problem-solving approaches, focused on preparation with the understanding that many other aspects of seeking care were out of their control. To ensure they were able to return to clinic when it was next required, participants found various ways to set aside money for transport:

If I know that this week is my appointment date...I keep the money for myself, know that I have this date, on the 15th I need to go to the clinic. If perhaps if I had money on the 12th, I will keep it for myself, then I will go to the clinic with money for lunch and travelling (PID26).

Another participant said that she sometimes relied on her mother to help her cover the cost of clinic trips (PID14). While not every participant was able to problem solve in these ways, these women were able to improve their odds of receiving much-needed preventative care by having some social support as a means to gain important access to financial and emotional support.

Facing recurring stockouts, some participants spoke about adopting more flexible approaches: stocking up on essential medicines from the pharmacy, or linking with other neighbors to procure medicines. Often, these experiences were communicated as hypotheticals to the interviewer:

Sometimes if my child is sick now...and the clinic is far away when I'm here, there is no transport and I'm here...what am I going to do? I have to take those medicines and help her in the moment (PID24).

Walking through a set of options, another participant described her reasoning:

PID26: If there are no medicines this week, you will stay and come back another week or buy yourself at the chemist [pharmacist].

Interviewer: If you don't have money for chemist?

PID26: If you don't have money for chemist, there is a[nother] clinic this side... We also go there, however they don't run out of them for long time here, they have them, but when they happen not to have them, we cross to that clinic.

Citing how far town was, another participant said if she were desperate to get her child's medicine, she would ask a neighbor or acquaintance headed towards town to help (PID3).

Lastly, relying on community networks in a different way, participants spoke about using their MMs as a communication channel to access care more readily. One participant noted that if a mobile clinic was scheduled to be in her area, her MM would phone her or her husband and indicate what time they should be ready and where they should go to improve chances of her baby receiving timely immunisations (PID5). Having a MM to both inform and motivate this participant allowed her to access alternative forms of health care more easily.

Although participants were not able to fundamentally change the nature of the problems they faced, they shared methods for coping in ways that increased their chances of better health outcomes.

Discussion

The barriers and challenges that pregnant women and new mothers face in accessing care have been well documented in LMIC settings; however, less is known about how women respond to these challenges. We set out to understand the health access experiences of pregnant women and new mothers in a remote, rural part of South Africa—and more importantly, to gather perspectives on how they individually navigate and respond to barriers to health care access. Participant responses at both interpersonal

and structural levels reflected diverse modes of navigating persistent barriers, yet also revealed an ongoing struggle to maintain motivation in the face of these challenges.

These findings illuminate the extent to which individual women engage in a broad range of strategies to cope and maintain dignity in the face of a health system that does not consistently serve them. They reflect similar themes to the case stories presented by Eyles et al. (2015), where South African health-seekers and providers alike detailed narratives of endurance, resilience and resistance. However, importantly, our findings also expose a level of exhaustion, disenchantment, and lack of trust in an institution established to provide equitable care in addition to (and in spite of) participants' navigating and strategising. As ongoing global initiatives attempt to improve the quality of maternal and newborn care, as a means to ensure dignity and equity for all women (World Health Organization, 2018d), these considerations are even more important. By paying attention to what women are already doing in this realm—to weigh their best chances of accessing services, and being seen and treated—we can begin to understand the complexity of their experiences and how to best frame policies for improving equity.

Other recent literature from South Africa helps put these findings in context. Passivity in patient-provider interactions is common in a traditional, paternalistic model of medicine (Kaba & Sooriakumaran, 2007). Such interactions are commonplace in rural settings in South Africa in particular, and may be driven by a lack of external or community-driven accountability mechanisms (Berlan & Shiffman, 2011; Cleary et al., 2013), poor supervision and leadership to drive quality care (Maphumulo & Bhengu, 2019), health worker burnout (Khamisa et al., 2017; Nesengani et al., 2019), and low health literacy (Safiya et al., 2009). For rural women, especially in the former “homelands”, hierarchies between patient and provider have been reinforced through the re-engineering of district-level primary health care (van Ginneken et al., 2010). It has

been argued in these contexts that a “covert contract” exists, where patients adopt the idea that they need to be a “good” patient (Frosch et al., 2012; Joseph-Williams et al., 2014), who does not question advice or actions of a health professional. Often, authoritative approaches from health providers, who may not engage patients in decision-making or attempt to use the encounter to support patients, can set the tone for unequal interactions. Other research has shown that providers may struggle to prioritise sensitivity in clinical encounters when there are more pressing structural concerns (Bhattacharyya et al., 2015). Likewise, from participant perspectives, “enduring” was seen as a default response. Many women did not see themselves as able to demand better care, further entrenching power divides between patients and providers as patients simply accept and “endure.”

We found that some women responded to both interpersonal interactions (e.g., facing poor treatment from health providers) and structural failings (e.g., experiencing repeat medicine and/or immunisation stockouts) with a diminished motivation to return to clinic. Other literature echoes these themes, with women who have experienced punitive treatment by health providers at clinics—for skipping appointments, for example—voicing a reluctance to seek care (Foster et al., 2010; Honikman et al., 2015; Munguambe et al., 2016). For some women, the financial cost of multiple return trips to check on medication stocks is not viable (Bedwell et al., 2017). These responses, while they may be a result of higher-level shortcomings, reinforce health inequities by decreasing the number of health contacts for mother and child and disincentivising the effort needed to receive adequate care.

The range of responses shared could also be framed as reflecting emotion-focused and problem-focused coping (Lazarus & Folkman, 1984). This model, devised by Lazarus and Folkman, differentiates coping responses to stress as either focusing on

managing the emotions associated with the stressor, or tackling the underlying problem causing that stressor. Some participants' responses were linked to personal feelings, especially when they faced recurring challenges: reflecting on these experiences was a way of sharing underlying frustrations that they felt unable to effectively change. Other women embraced more active, problem-based coping mechanisms, by attempting to prepare for adverse circumstances, or carrying out small acts of resistance. Some participants specifically mentioned the instrumental function of their MMs, facilitating access to immediate care or identification of a health problem in a way that had not been previously possible. However, overall, problem-based tactics were often more restrained. Unable to seek further care because of financial constraints, women spoke of returning home empty-handed; unable to be seen and treated as individuals in an overburdened clinic, many opted to stay quiet or "endure" instead of openly defy a health provider. While participants described finding small ways to "gain power," it is important to recognise that not all were able to channel this approach. Importantly, a number of participants detailed both types of responses.

While South Africa's health system is rooted in a history of fragmentation and inequity, other similar countries, such as Brazil, have found success in integrating the public health system to be more aligned with the needs of poor communities (Jurberg, 2008). Brazil's primary health care-focused Family Health Strategy utilises health teams including one physician, one nurse, one nurse assistant, and up to six CHWs, which serve pre-defined catchment areas (Andrade et al., 2018). Despite variability in health-seeker experiences, studies gathering patient perspectives have found generally high satisfaction with geographical accessibility, acceptable services, and interpersonal interactions (Fausto et al., 2017; Gaiosio & Mishima, 2007). Although CHWs such as Enable's MMs can provide motivation and social support for pregnant women and new

mothers who may struggle in accessing routine care, they operate as an add-on to the government health system rather than an integrated part of it. As such, Enable still relies on a separate functioning health infrastructure to accomplish programme goals, unable to replace formal health services (Tulenکو et al., 2013). For programmes designed to connect clients to resources, expand health education, and promote uptake of safe preventative health practices, an absence of adequate services, as well as structural barriers to accessing formalised health care, can limit the scope of these programme goals, or render them unattainable (Blacklock et al., 2016; Kok et al., 2015).

Implications of these findings

Our findings highlight both interactive and active responses by pregnant women and new mothers as they faced considerable challenges in accessing care for themselves and their infants. Making women more aware of their health rights is a central part of confronting these persistent challenges, however, these efforts must take place within a broader enabling environment. These findings illustrate the need to prioritise supportive patient-provider interactions in clinical settings, and to integrate these interpersonal approaches with more innovative solutions that can increase access to care. Promoting principles of shared decision-making in pre-service and ongoing clinical training, which is well-theorised and researched between doctors and patients, could be an important first step, with primary health care professionals encouraging and preparing patients to actively participate in the clinical encounter (Joseph-Williams et al., 2014). This approach has been shown to improve patient satisfaction, preserve a sense of patient dignity and autonomy, and reduce the burden on the physician (Schain, 1980). Women's satisfaction has been found to be correlated with provider empathy in low-income settings, especially among women who recorded experiencing birth complications

(Bazant & Koenig, 2009): this speaks to the importance of recognising that across all contexts, interpersonal aspects of care should be emphasised equally alongside structural improvements. However, this approach necessitates equipping health providers with the necessary skills and competencies to supportively engage patients at all stages of the medical encounter and provide empathic professional services. Improving provider communication skills and giving space for patients to provide feedback may enhance the quality of care, even in overstretched health facilities (Pantoja et al., 2017).

On a more immediate level, for CHW programmes in LMICs in particular, it is imperative to establish strong linkages between these types of programmes and existing primary health care infrastructure. In the foundational work that happens before pilot programmes are implemented, or successful models are taken to scale, targeted communications with locally-embedded health facility management are essential. Lastly, mobile clinics may be an important bridging mechanism, delivering health care services to remote communities and making services more accessible for the most vulnerable who may struggle to travel to bricks-and-mortar clinics (Yu et al., 2017).

Limitations

By virtue of our participants' inclusion in a home visiting programme, they are not necessarily the most vulnerable—they ostensibly have more available support and a better grasp of relevant, essential health information. However, their experiences reflect typical health care experiences of women of childbearing age in their setting as corroborated by programmatic staff and co-residents. For this reason, they are central to providing a more detailed picture of patient perspectives and how health care services in remote places operate. Further research disentangling barriers to care might encompass interviewing a larger sample of women, or incorporating a more detailed observational

or ethnographic data collection effort recording barriers to care across a range of methods, such as journaling or case note/record review.

References

The references for this article can be found integrated into the final References section of this dissertation, beginning on page 169.

Chapter 7: Discussion

Chapter outline

In the previous section, I presented four chapters addressing diverse aspects of Enable's implementation. This final chapter weaves together conclusions from these findings and outlines the implications of this dissertation. Following a brief summary section, I structure this chapter around three emergent contributions, which reflect the gaps first introduced in Chapter 1, and a final overarching implication. I end this chapter with recommendations for practice and research stemming from this dissertation, and a brief conclusion.

Summary of research aim

I set out to explore the processes underpinning the delivery of a CHW programme, Enable, in rural South Africa. I gathered detailed data about the experiences and interactions that characterised client-MM relationships, and how these relationships were embedded in a greater health and social context. In so doing, I examined how these processes shaped the way in which the Enable Programme was delivered.

My study, which combined interview data from Enable's clients and MMs as well as audio recordings of home visits, identified important findings related to fidelity to training, client responses to the programme, and contextual factors affecting implementation. These are essential components of this dissertation's guiding model, the MRC Framework for process evaluation of complex interventions (Figure 1, p. 10). Two of the chapters reproduced in this dissertation have been published as articles in *Social Science & Medicine* (Laurenzi et al., 2020) and *Research in Nursing & Health* (Laurenzi et al., 2019), with the remaining two chapters revised and resubmitted, and under review, respectively.

These findings from this dissertation link to other research on CHW programmes, and add to a growing body of literature that seeks to consider the circumstances in which CHW programmes are effective, and the challenges with taking programmes to scale (Perry et al., 2017). Each of these areas is described in more detail in the three contributions that follow.

Contributions to knowledge gaps

In this section, I discuss three core contributions from my dissertation. At times, I focus on specific outputs from individual articles, but each contribution can be applied across all of the findings included in this dissertation.

Contribution 1: CHWs should be trained and continually supported to utilise interpersonal skills in their work.

The findings of this study address two gaps related to how training connects to the implementation of CHW programmes. Firstly, there is limited research on how CHWs use interpersonal skills in their work, despite an understanding that training on interpersonal skills is necessary for effective implementation. Secondly, there is limited follow-through of these types of skills after training, although this link between training and practice in field settings can support their continued use. In this section, I review each of these gaps, and then describe my contributions towards answering them. Specifically, I focus on contributions related to communication and self-care skills and discuss how programme leadership may strengthen opportunities for training in each of these areas.

Limited research on interpersonal skills in CHW settings. Interpersonal skills are commonly spoken about in programmatic guidance on training and named as

prerequisites for high-performing CHWs (Cometto et al., 2018). Training CHWs on specific knowledge and skills is generally accepted as critical to building organisational capacity (Allen et al., 2016), and this training may include interpersonal competencies needed for the role (O'Brien et al., 2009). However, research on how to encourage these types of skills, as well as the impact of integrating them in practice, are often missing from research with CHWs (Scott et al., 2018). Two specific interpersonal skill areas stand out: communication skills, and so-called “self-care” skills. Communication skills may include the ability to deliver health advice effectively, probe a client for more information, or build rapport with clients (Laurenzi et al., 2019). Interpersonal skills are not only about creating connections, however. The ability to engage self-care skills—which includes setting boundaries within often-challenging work environments—is critical (Roche et al., 2013). Limited research explores these issues within CHW programmes or considers the impact of burnout on CHWs who may struggle with this kind of interaction-related self-care (Pandey & Singh, 2015). This focus area is important both for ensuring individual wellbeing and promoting the longevity of a community-embedded workforce (Selamu et al., 2017). Because these skills are not well-researched, there is limited understanding of how they may affect programme implementation, or how to improve the way in which these skills are taught and later “refreshed”—presenting a critical gap in how CHWs are equipped for their roles.

Tracing the link between training and practice. A second, related gap in this field is that there is a disconnect between training and practice: we do not have a strong enough understanding of how what is really happening in home visit settings compares to what was taught in training (Schodt et al., 2015). In addition to the first gap in research about these types of skills, there is also a gap in monitoring by programmes themselves. This kind of monitoring or tracking of fidelity to training in interpersonal

skills can be challenging (Breitenstein et al., 2010). Supervisors in CHW programmes may face competing demands to complete other tasks, or may lack transport required to accompany CHWs and to assess these skills in practice (Akintola & Chikoko, 2016). It may be difficult to isolate or capture particular skills during routine supervised visits if supervisors are paying closer attention to the content and relevance of the intervention provided, which may take precedence (Wilford et al., 2018). Finally, CHW experiences of blurring boundaries and balancing their own needs often happens internally, or outside of programme contexts, making this process difficult to observe (Pandey & Singh, 2015). The lack of understanding of what actually happens in client-CHW interactions, versus what CHWs are trained to do, limits the quality of implementation efforts.

Responding to these gaps. In this dissertation, I attempted to close some of these gaps, and to trace the link from training to practice in the Enable Programme. My two contributions relate to communication skills and self-care skills—specifically, how to measure them and consider them in the context of training. As training can establish foundations for client-centred care, from which strong relationships can flourish, I consider implications for integrating each of these areas into training more specifically.

Integrating and refining the HCSI. The HCSI, developed over the course of this dissertation, represents a response to some of these challenges in mapping fidelity to training for communication skills. It consists of simple, evidence-based, and programme-tailored categories; it allows complex practices to be quantified and grouped for easier analysis; and it can be applied using less intrusive, low-cost methods (Laurenzi et al., 2019). Its three main domains—active listening, active delivery, and active connecting—categorise three distinct but related sets of communication skills. In the pilot of the HCSI using audio recordings of Enable home visits, communication skills were observed with

relative consistency across all MMs; however, MMs were less likely to engage a diverse set of active connecting skills compared to the other two domains.

While researchers have recorded and later analysed interactions between patients and providers in clinical settings in LMICs (Abdel-Tawab & Roter, 2002; Kilian et al., 2015), and between home visitors and clients in high-income settings (George et al., 2016; Schodt et al., 2015), there was no precedent for recording home visiting sessions in this study's research setting, a rural district in South Africa (Laurenzi et al., 2019). Home visit data from client-CHW interactions, representing “snapshots” of individual visits, enabled similar analysis to work that has been done with individual encounters between clinicians and their patients (Kim et al., 2002).

The HCSI represents a more defined, quantifiable attempt to track the link between training and practice and provides a roadmap for programmatic use. The HCSI and tools like it might provide a starting platform for supervision meetings and discussions of interpersonal challenges encountered on the job; they may be modified for group-based discussions or role plays, too. At the same time, the HCSI would also benefit from further refinement and improvement. As a tool for assessing fidelity, it was robustly conceptualised using a combination of best practices and the Philani intervention manual (King & Hoppe, 2013; Philani, 2016; Roter, 2000a). While it meets a gap in linking training to practice, it might require fine-tuning, programme-specific adaptations, and further testing before it is used more widely.

Supporting self-care for CHWs. This study also identified challenges that Enable's MMs faced in practising self-care skills as they were trained to. Interviews with MMs revealed how they approached their roles and responsibilities in the context of personal and community expectations. MMs echoed lessons from their pre-service training in recalling that they were not supposed to take on their clients' burdens; however, many of

them struggled to detach from the challenges they encountered in their daily work when they arrived home. Some of these MMs acknowledged that, because they had made the decision to shoulder these burdens, or engage in after-hours work, they bore responsibility for the added stress. These challenges were also mirrored in the client interviews, as clients described the diligence and availability of their MMs. A smaller number of clients articulated a sense of uncertainty around the scope of the MM's role, indicating that they did guard some personal information that they felt was out of a MM's purview.

These findings connect with a limited literature on supporting CHWs and point to the role of training to bolster these skills (Selamu et al., 2017). Firstly, training may be able to promote more defined ideas of what the CHW role can be—and how to identify different means of self-care and protect from longer-term burnout that may occur in the absence of such practices or skills (Akintola et al., 2013). Training sessions, including both pre- and in-service training, can become platforms for communicating expectations and creating an acceptance around setting boundaries and stating limits. It may be particularly important for CHWs to understand that they can show empathy to clients and commitment to their role while simultaneously determining how closely, or deeply, to engage (Pandey & Singh, 2015). This framing may include what Gale and colleagues refer to as “synthetic social support”—which bounds the interactions between lay health workers and clients while still preserving key elements of the therapeutic relationship (Gale et al., 2018). As many CHWs are lay women who have not held formal jobs before, these notions may not be assumed, and should be communicated regularly.

Secondly, CHW wellbeing in their roles may rely on opportunities for further support in training settings, including skills-sharing in self-care, debriefing, or reflection

(Kok et al., 2018; Tseng et al., 2019). Linked to this, training or regular team meetings may be important spaces for mutual support and sharing, especially for individuals who have less experience in health-focused or other demanding occupational environments (Roche et al., 2013). Supportive supervision may also be important, where MMs can be encouraged to set their own parameters regarding client engagement and goal-setting, for example, and then supported to monitor their own progress and discuss challenges (Kok et al., 2018). Additional programme-specific adjustments might be required, however, to ensure that this support is well-received and sustained.

Broader implications for scale-up. This contribution links to broader questions about scale and sustainability of CHW programmes. The process of tracking fidelity to training begins with pre-service selection and training but also needs to extend throughout the course of programme implementation. Ensuring that interpersonal skills are prioritised, embedded, and followed up is important for high-quality implementation: it is also critical to retain in programme protocols if and when programmes expand (Hodgins et al., 2013). While training standards and ways of measuring fidelity should be flexible to some degree—able to adapt or absorb new information to make programmes more effective—they should also be clearly laid out and communicated from early on. Digital tools for tracking fidelity, which have been successfully used in high-income settings (Rotheram-Fuller et al., 2017), may provide ideas for how to innovate but also preserve core programme expectations during scale-up.

Summary. In this dissertation, I have responded to gaps in understanding how training translates to practice for CHW programmes with a focus on ensuring fidelity. My findings from MMs and clients contribute to a more comprehensive understanding of how training and support could be utilised to develop and enhance core skills related to interpersonal skills, and communication and self-care specifically.

Contribution 2: Supportive, dynamic relationships are central to the implementation of CHW programmes.

Relationships emerged as core to client and CHW experiences with the Enable Programme within the interviews conducted for this dissertation. Relationships, and the requisite skills for establishing and maintaining them, are embedded within conversations around CHWs and their roles (Perales et al., 2018). However, relationships have often been absent from understandings of how CHW programmes work, especially in LMIC settings. In part, this gap links to voices missing in the research: understanding from clients as well as CHWs what parts of these relationships are most valued, and how they may drive implementation and behaviour change.

In this section, I describe what supportive relationships can look like in my findings and the literature. Next, I discuss the dynamic aspect of these relationships, and how this particular aspect may activate additional pathways to behaviour change and empower clients and CHWs alike. I close this section with some implications for practice.

Describing supportive relationships. In in-depth interviews with Enable clients and MMs, both types of respondents placed high value on relationships, characterising their relationships with one another as a central part of their experience with the programme. Instructive interactions included sharing information, ensuring comprehension, demonstrating techniques, and listening to client concerns. These interactions reflected the central purpose of Enable, as a preventative health programme designed to increase access to important health education and care. Supportive roles and relationships were described as part of a longer continuum, built over time and reinforced through interactions (Laurenzi et al., 2019). This more supportive quality was

characterised by clients and MMs as being built within the context of the home visit, but also affirmed outside of it, through additional phone calls and personal check-ins.

My findings build on existing work documenting the importance of patient-provider relationships in promoting high-quality care (Roter, 2000a), including research that has been conducted in clinical settings in LMICs (Kilian et al., 2015; Kim et al., 2002). It also contributes to research from home visiting programmes, which rarely report on clients' perspectives. For South African women experiencing multiple, intersecting vulnerabilities during and after their pregnancies, the type of support that they receive through the home visiting relationship can be essential to their accessing necessary services for their own health and their child's health (Lund et al., 2020; Rotheram-Borus et al., 2015). Similarly, CHWs may feel motivated by the ability to identify clients' needs and tailor their support accordingly (Kok et al., 2018). Although the relationship takes diverse forms based on the individuals, the cultural background, and the broader environment in which the programme is being implemented, this research reiterates the importance of gathering perspectives from both sides, as a means to better understand the dynamics of these relationships.

Relationships as contributors towards behaviour change. Secondly, it is particularly important to understand these relationships in terms of the downstream effects they may have. Many of the client-CHW relationships that emerged from these findings can be described as dynamic and empowering. Thus, they have value not only for the quality of information or support they might provide, but for the ways in which they might lay foundations for individual empowerment and behaviour change in the future.

Limited research examines relationships and relationship quality as a driver of how CHW programmes actually work (Roggman et al., 2016). One component of

understanding relationships between clients and CHWs, and how they can be leveraged to improve delivery, is through supportive supervision. Supportive supervision is typically defined as a process of facilitation between a health worker and supervisor (Marquez & Kean, 2002). Evidence from formal health care settings emphasises the importance of supervisory relationship quality in producing a higher standard of care and service delivery (Bailey et al., 2016). It is clear that supportive supervision can provide modelling and inspire confidence for health workers, including CHWs (Kok et al., 2018). However, little research exists—especially on CHW programmes in LMICs—that investigates relationship quality between CHWs and their clients, and how these relationships might be activated to drive behaviour change (Korfmacher et al., 2007).

The clients and MMs interviewed found ways to rely on these relationships to meet their needs. Clients reported leveraging their relationships with their MMs in a health facility setting, through furnishing a referral letter, for example. MMs, similarly, spoke about making connections with clients that put them at ease, or made them feel good about themselves, to lay foundations for a longer-term engagement. There were also more tangible examples of instrumental support, where MMs provided once-off meals or after-hours phone calls to support particularly vulnerable clients. Each of these practices, taken together, start to form a picture of how programmes may be received and responded to.

The dynamic quality of many of these relationships—which might shift over time or confer a new sense of agency—emerged as less defined, but equally if not more valuable. This included concepts such as mutual respect, which many participants spoke about, and the sense of accountability that followed from this feeling of respect. It also encompassed a right to self-determination, which is embedded in Philani's training manual, and which emphasises the autonomy and agency of the client (Philani, 2016),

and is similar to shared decision-making models in clinical medicine (Schain, 1980). A number of clients shared in interviews that they felt comfortable being honest with their MMs about not following advice. To clients and MMs alike, this type of relationship was described as a powerful driver of programme effectiveness—even in situations where programme goals were not always met.

Empowerment leading to change. Inherent within these descriptions was a sense of empowerment underlying the individualised, extended contact that MMs and clients had in their home visits. While empowering clients is a goal of many CHW programmes on paper, the vertical, technical aspect of most CHW programmes in practice has advocated “easy wins” to improve targetable health outcomes, in place of long-term, sustained efforts for health equity (Rifkin, 2018). Individual client qualities, as well as implementers’ preferences, skills, and competencies, can affect the extent to which these relationships form, and flourish (Brookes et al., 2006). However, CHW programmes and those who design and implement them must place high-quality relationships, with an aim to empower, at the centre of their models. Empowerment can and should also be seen as a form of sustainability – fostering intergenerational capacity at a community-wide, peer-delivered level.

This process of client empowerment, however, should not be taken for granted, nor assumed to be linear. Certain clients require more assistance or support to be able to advocate for their own health and that of their children—especially in the context of intergenerational poverty, disenfranchisement, and persistent negative experiences in health care settings (Castaneda-Guarderas et al., 2016). This reality is made abundantly clear in the challenges and responses documented in clients’ accounts of health-seeking (Laurenzi et al., 2020). It is also echoed in the findings from MMs, who themselves are managing competing responsibilities in low-resource settings. Nevertheless, supportive

relationships in which clients' rights are respected and recognised provide a powerful foundation for further health behaviour change and motivation (Joseph-Williams et al., 2014). Relationships based on mutual support and accountability further provide a counterweight to the daily challenges facing MMs and clients alike, serving as a motivating force for health-seeking or intervention delivery, despite considerable odds.

Understanding how to promote relationships. While the centrality of relationships in CHW programme implementation is evident, it is important to understand how to carry this contribution forward. Over the course of the implementation of a CHW programme, relationships may be diverse, changing, and not always easy to develop or measure. My findings point to three areas that might shape further ways that CHW programmes understand and operationalise relationships.

Challenge the assumption of inherent connections. Firstly, for CHWs in particular, the ability to form “natural” connections with target populations has been presented as a defining factor (Lehmann & Sanders, 2007). Many theories about CHW programmes' effectiveness rests on the cultural, social, and economic similarity between CHWs and the populations they serve (Azzi-Lessing, 2013; Kilpatrick et al., 2009); this connection is seen to play an instrumental role in developing individual relationships as well as linking to broader effectiveness (Olaniran et al., 2017). This ease of connection emerged from Enable's clients and MMs, too. MMs described the importance of being “known” and seen as a trustworthy community figure, and clients similarly spoke about approachability and comfort.

However, these interviews also revealed that these connections were not necessarily a given, and that relationship-building required sustained efforts. MMs described relationships that were predicated on a sense of humility and integrity (living what they preached), and that acknowledged the importance of fostering, and

maintaining, a high level of trust. Therefore, while assumptions about community and local buy-in may be important motivators for CHW programmes, their logic may also oversimplify the process of relationship-building between CHWs and clients. In this way, they may minimise the need for more focused training, support, and monitoring of relationship quality in both nascent and long-established programmes. Continuing to recognise the strength of community connections, while understanding how they can be bolstered, is important for CHW programmes as they are implemented.

Systematically gather perspectives from clients. In addition to routine supervision and support for CHWs, client perspectives on the programme, and their relationships with CHWs, may be able to be incorporated in implementation efforts more regularly. They might provide an opportunity to review programme delivery efforts or indicate “blind spots” for further attention. For example, in my interviews, clients spoke about the value of a MM demonstrating specific teachings with props or changing her tone when communicating something especially important. Client perspectives can also be expected to be diverse, drawing from a larger sample than would be available with drawing information from CHWs only. This variability can be expected across any type of community health programme (Wallerstein & Duran, 2010), but also drives decisions about how to allocate time, effort, and investment in developing skills related to implementer competence. These kinds of feedback channels might assist programme leadership as well as researchers to recognise how relationships influence the way in which programmes are delivered, responded to, and sustained (Ludwick et al., 2018).

Balance relationships with the need for boundaries. Finally, it is important to recognise that the need to prioritise relationships should be balanced with, and tempered by, the realities of community-based work. Specifically, considerations about prioritising and building programmes around client-CHW relationships should do so in a way that is

also protective and avoids additional work-related stressors (Pandey & Singh, 2015). This point is intrinsically linked to self-care skills and training that equip CHWs with the tools to set boundaries, communicate expectations with clients, and determine the extent to which they will make themselves available outside the scope of the workday. In promoting supportive, warm, and responsive relationship qualities, it is also possible and desirable to identify ways to support CHWs themselves.

Negotiating space, and roles, may become more difficult for CHWs like Enable's MMs who are funded through NGOs. In South Africa, for example, these types of CHWs are operating in parallel to government health providers, paired with a formal health system to facilitate linkages (Nxumalo et al., 2016). They stand in contrast to increasing numbers of government-funded CHWs, who have become recently integrated into WBOTs (Schneider et al., 2018), and who may face a different set of expectations from supervisors as well as community members. In South Africa, these teams may exist side by side, complicating the health services landscape for both providers and clients. Considering how to balance between community membership and professional roles is important for both types of community-based health providers, and will remain a priority as WBOTs are continuously implemented nationwide (Department of Health, 2017). These considerations may extend to other LMICs where governments have made a more concerted effort to integrate and adopt CHWs that have historically been employed by other organisations.

Summary. In this dissertation, I have responded to gaps in understanding how relationships contribute to programme implementation by engaging with clients and implementers alike. One of the strengths of this dissertation is complementary sources of data from which I draw out this nuance and complexity in client-CHW relationships.

My findings also emphasise the importance of relationships in laying foundations for client agency, empowerment, and behaviour change.

Contribution 3: Contextual and environmental challenges cannot be overlooked, as they significantly influence how CHW programmes operate.

I focused on context as the setting and conditions in which the Enable Programme was operating, including: the community-based nature of the programme, the physical environment in Nyandeni Municipality in which clients and MMs lived, and the personal lives and experiences that clients and MMs brought to bear on their engagement in the programme. Previous research has overlooked the critical role of contextual factors in how CHW interventions are implemented (Blacklock et al., 2016; Kok et al., 2015). I found that clients and MMs engaged in processes of negotiation and navigation in their lives and with regard to Enable. They balanced responsibilities, shouldering the burden of these duties largely on their own or with limited supports. Furthermore, as they attempted to fulfil their roles in the programme, contextual factors often complicated these efforts.

In this section, I discuss the contextual challenges that MMs and clients spoke of navigating, as well as some of the inherent tensions in their programme participation. I then expand to focus on broader implications for sustaining programmes over the long-term, and at scale. My final discussion centres on limitations of CHW programmes, especially where health systems function poorly.

Meeting demands and navigating boundaries. For most CHWs, their roles are inextricably linked to their context. Their potential, as low-skilled health workers, is tied up in concepts of them as culturally and socially similar to their communities (Lehmann & Sanders, 2007). At the same time, by virtue of their training, employment, and innate

motivation, CHWs often stand out within their own poor communities as arbiters of information and mediators to health services (Zulliger et al., 2014). This tension is reflected in my findings: MMs were both peers and advisors, confidantes and providers. MMs tried to fulfil the demands of a professional job, utilising their training, skills, and potential new connections, to facilitate access to care and a sense of support for their clients. In placing pressures on themselves to “live” their roles, most MMs found it challenging to disentangle their own personal needs from those of their clients. This conflict was further echoed with MMs wanting to be seen as role models, finding common ground with clients while also modelling good behaviour. The nature of this work was described as both a challenge and a burden, although some MMs found ways to self-protect against feelings of stress or guilt. This friction, however, was typically a function of the embedded nature of MMs in their communities.

Clients, in turn, tried to be “good patients” (Frosch et al., 2012) and mothers, seeking care for themselves and their children, finding ways (and sometimes also failing) to circumvent persistent challenges. Clients’ accounts of health-seeking were intimately connected with their participation in, and accountability to, their relationships with MMs. In seeking health care, they may have been attempting to fulfil their role in the client-MM relationship, and also do right by their infants. However, it is important to note that the process of navigating was still a more challenging process for the clients whom Enable serves due to their marginalised status as poor, rurally-based women (Laurenzi et al., 2020). The realities of their experiences, in seeking care outside of the context of the Enable Programme, should not be left out of discussions around client empowerment and motivation.

Considering limits and possibilities linked to context. Because contextual factors external to programmes are at the root of many of the challenges facing clients and

CHWs (Kok, Broerse, et al., 2017), these factors must be clearly identified and defined as programmes are implemented, and later evaluated. Other research has included a focus on contextual influences to mobilise research for improving policy and programming efforts (Kok et al., 2015; Schneider et al., 2008; Swartz & Colvin, 2015). My findings enhance this body of work by contributing more nuanced qualitative analyses on how context not only limits but also encourages responses among clients and MMs alike. This approach, and similar research, acknowledges the tension inherent within these types of programmes: that they can be both empowering and limiting.

In order to support CHWs, it is important to gain a clearer understanding of the personal and professional boundaries that they are asked to negotiate. However, this topic requires further work and more robust understanding. For instance, while I have suggested encouraging programme leadership to set boundaries and define roles more clearly, this act is also fraught. Many CHWs carve out their own sense of value based on their commitment to work (Busza, Dauya, Makamba, et al., 2018; Swartz & Colvin, 2015). As such, encouraging them to be more distant from clients seems at odds with the other contributions from this dissertation, as well as perhaps at odds with what CHWs themselves would find acceptable. What space can there be for the unspoken burdens that CHWs take on? Should we leave room for these additional duties, while teaching CHWs how to navigate appropriate boundaries? The answers to these questions are dependent on the context and environment in which CHWs operate and should rely on the input of CHWs themselves.

Broader questions for sustaining CHW programmes. On a broader scale, these implications may affect how we approach CHWs as a workforce, as both community-embedded and professionally equipped. Does task-shifting create undue burdens for these women? While CHWs, like other health professionals, need to make decisions

about who to see, and how to structure their days and their time, they are also confronted with an ever-expanding portfolio of tasks (Smith et al., 2014). In the case of Enable's MMs and many other CHWs, they also have appointments to get to on foot. Therefore, the debate over task-shifting is about often-mundane duties, but also about what we are asking of these programme implementers in their specific environments (Dambisya & Matinhure, 2012). This framing also puts CHW programmes into a more complicated ethical perspective: questioning a reliance on lay workers, who are predominantly poor women, to take up the mantle of health care provision for their own communities. This reality may be balanced by women's experiences of gaining skills, earning a salary, and channelling a sense of purpose into the role, but it should also be considered from a broader structural perspective.

Beyond task-shifting, there is also a need to think about connecting to longer-term aims and making programmes sustainable and eventually scalable (Fletcher et al., 2016). This process can only be done with careful detail and connection to context (Mirzoev et al., 2016). Despite the overall "successes" of the Enable Programme—satisfied clients, high levels of skills transfer, and implementers who feel a sense of purpose—these factors do not always translate meaningfully to improved health outcomes for its clients. Persistent structural barriers to formal services play a significant role in this specific instance (Laurenzi et al., 2020). However, while contextual factors must be considered in efforts to strengthen programme foundations, short-term needs may disincentivise long-term planning. For example, in other programmatic settings, CHW programmes seeking additional funding or recognition may deliberately overlook the role of context, pursuing deliverables or performance indicators without regard to how these results are obtained (Hodgins et al., 2013). These "successful" programmes then go on to scale, and tend to

lose effectiveness (Olds et al., 2003). When programmes start small – and when they go to scale – these considerations need to be laid out.

In understanding the role that context plays, programme designers can draw upon not only the barriers to effective implementation, but the existing strategies that women may use to navigate challenges (Holeman & Kane, 2020). To ensure a return on the considerable time, energy, and investment that go into implementing a preventative health programme, these efforts need to integrate what is already happening with evidence-based practices (Schneider & Lehmann, 2016). This approach would ensure a higher possibility of sustainability and encourage buy-in.

Stepping in to meet basic health needs. This work brings to light a more sobering reality: one of persisting barriers to basic health care and services. Enable initially targeted a specific ward in the Nyandeni Municipality for its remoteness and dearth of existing health infrastructure, and the MMs and clients who contributed to this work continue to live, work, and seek health care in this area (Whiting, 2017). My dissertation thus evokes a more critical reflection about the overall utility of CHW programmes in resource-poor contexts. Because of the longstanding structural and environmental constraints facing individuals and families in Nyandeni, in many cases challenges in accessing health care persisted despite the best efforts of MMs and clients. “Membership” as a client of Enable conferred intermittent benefits to clients, in cases where they arrived at clinics with referral slips that clearly explained an issue that needed to be addressed during the consultation. However, these experiences were far from universal. Many more clients shared accounts of medication stock-outs, long walks to and from clinics, or onwards referrals to hospitals—for services they needed but on transport they could not afford (Laurenzi et al., 2020). These experiences with formal health care, though expected, were still demoralising.

Echoing other work, these data show that the South African government health system is not adequately serving the needs of poor women, even those who are ostensibly helped by a parallel programme (Eyles et al., 2015; Scheffler et al., 2015; Schoeman et al., 2010). As such, the MM model relies on a functioning formal health system to complement its service delivery, and to ultimately support the improvement of maternal and child health outcomes (Kok, Broerse, et al., 2017). These findings indicate that CHW programmes cannot and should not be seen as a catch-all solution to high demand and overburdened providers and facilities. To meet the needs of clients as well as implementers, these programmes must exist in tandem with structural-level health systems strengthening and advocacy efforts (Schneider & Lehmann, 2016). These findings also serve as a valuable reminder that, outside the bounds of community-based interventions, women have long had to find ways to circumvent challenges and create their own solutions (Eyles et al., 2015). This dissertation has sought to document both the inherent agency that these clients and MMs draw upon, as well as the factors that continue to constrain the options available to them.

Summary. In this dissertation, I have responded to gaps in understandings of how contextual elements affect CHW and client experience and engagement in programmes. My findings indicate CHWs and clients engage in meaningful and mutually accountable client-CHW relationships; however, these interactions, at the interface of the programme, are also framed by limitations. Importantly, I use this contribution as an opportunity to question the continued application of CHW programmes that do not adequately account for context, especially in the face of constrained, poorly-functioning health systems.

An overarching need for a human-centred approach

Taken together, the implications emerging from this study highlight the need for a more human-centred approach to how CHW programmes are implemented. This “human” element, at the core of processes related to building and maintaining relationships, and navigating roles and responsibilities, is continually overlooked. As I have noted at different points throughout this dissertation, CHWs continue to be deployed as a more technical workforce across multiple countries and embedded in programmes that are scaled rapidly to meet ever-growing population needs. This technical framing has at times been a product of importing unsuitable solutions to LMIC settings, or attempting to retrofit policies or models that have been established elsewhere (Schneider, 2019). Furthermore, as Enable shows, even when the intervention model is locally developed, there are still challenges with translation and scale – for example, with bridging an urban-rural divide as wide as South Africa’s (Besada et al., 2020). Through the policies surrounding WBOTs, South Africa may soon see a move towards a more comprehensive, less hierarchical approach to health for all (Schneider & Nxumalo, 2017). But as with all CHW-driven models, human-driven aspects of implementation, equity, and context will all be core to the success of these teams.

The key contributions from this dissertation, and the recommendations for practice and research that follow, represent a call to centre around human-based elements of care provision. In some respects, this framing goes back to the original Declaration of Alma-Ata (Rifkin, 2018), and echoes some of the more recent work towards universal health coverage (Tangcharoensathien et al., 2015; World Health Organization, 2018b). Yet it also restores focus to the ways in which clients and implementers might be able to drive how community health programmes are implemented. Within CHW programmes, this would be a way to keep clients’ and

implementers' priorities at the centre of the intervention, and not make assumptions about what is best for people, especially those who are already marginalised (Daniels et al., 2012). In this way, community health interventions could continue to be focused around education and prevention, but also combined with a sense of empowerment and support along the project's implementation.

Human-centred design, along with processes of co-development and consultation, has recently gained a broader following and more momentum in community health research and implementation science (Holeman & Kane, 2020). A human-centred approach may be able to incorporate relationships and community context, while also relying on an evidence base for best practices in home-based and community-based interventions. Further, just as human-centred principles can draw upon the best evidence to make interventions effective, processes of scale-up that move beyond being defined around narrow framings of evidence and scientific efficacy. This approach would entail a more inclusive, responsive, and pragmatic version of scale-up that incorporates relationships and context as critical elements.

Recommendations for practice

In the brief section that follows, I summarise four recommendations for practice and programming that stem from the findings of this dissertation. These recommendations are: 1) training that prioritises communication and competence, 2) opportunities for community consultation and engagement efforts, 3) pathways to professionalisation, and 4) strengthening systems through increased communication and advocacy.

Training that prioritises communication and competence

Firstly, my findings emphasise the need for programme developers and implementers to focus on communication skills, and the relationships that rely upon them—specifically, during selection, training, and supervision. For programme leadership and policymakers looking to invest in a longer-term vision of a sustainable and scalable CHW workforce, establishing these skills as critical from the outset is important (Ingram et al., 2012).

Training should cover a number of critical functions, including but not limited to: communicating expectations and programmatic values, teaching core implementer skills, supporting teams across skill levels, setting ground rules for boundaries and self-care, and/or identifying continuing areas for improvement (O'Donovan et al., 2018).

Programme leadership, by prioritising programmatic values and expectations that include relationship quality, communication skills, and self-care, can send a powerful message to CHWs that time spent engaging in relationship-building—and not just task completion—is valuable and valued. Establishing communication skills and client-focused relationships as core tenets of a CHW programme might involve framing trainings, discussions, and supportive supervision around how to establish and enhance relationships (Allen et al., 2016).

Training platforms can comprise formalised, structured sessions; they can also take the form of informal, small-team get-togethers, or embedded, within-visit opportunities for continued learning together on the job. Training might involve creating opportunities to engage in peer-to-peer learning and sharing around topics linked to implementer competence (Kok et al., 2018). There may also be further scope to include principles of adult education, which have been employed with other community-based health programmes (Nebeker et al., 2015). These principles includes learning by doing,

equal treatment in learning environments, integrating existing experience and knowledge, flattening hierarchies between trainer and trainees, and goal-oriented and applicable lessons (Simelane et al., 2018). These forums could facilitate knowledge and skills transfer from more capable or experienced staff to those who may struggle more to connect with clients. While my dissertation does not focus closely on the role of teams, or MM-MM relationships, in the implementation of Enable, these connections may be important to further explore. Training that utilises existing in-programme partnerships might include co-supervision to facilitate non-judgmental, mutually supportive interactions, or seek to develop relationships between supervisors and CHWs in a more focused, structured way.

Opportunities for community consultation and engagement efforts

Secondly, communities served by CHW programmes should be the first port of call for human-centred service delivery. Consultations with “end-users” or those who benefit from the programme consider the role of the client, and the communities in which programmes are implemented, in driving how interventions are implemented and “owned” (Naimoli et al., 2015). Often CHW programmes have in-built processes for initial consultations and engagement of local or traditional leadership. However, promoting principles of equity early and often is critical for programmes to be effective, flexible, responsive, and fully targeted towards the populations they serve. These kinds of engagements can act as a counterweight to clients’ experiences of inequality and indignity in health-seeking.

Clients’ and communities’ understanding of their roles in taking interventions forward is key for building a theory of change and understanding how clients can be involved when these programmes are taken up to scale. We can learn from clients

themselves about how to bring groups together more effectively, and how their feedback can be integrated into how the programme is run (Holeman & Kane, 2020). In rural South African settings in particular, where community advisory board are common, these modes of engaging around a problem, topic, or policy might be particular useful in the context of improving CHW programmes.

Importantly, there should be no rush to expand and scale before these pieces are in place. Programmes can be built on evidence, framed around local solutions, and promoted through human-centred training and capacity-building; community consultations provide a concrete example for how these factors might come together.

Pathways to professionalisation

Thirdly, within CHW cadres, as well as within other health professions, there is a need for improved role definition and an understanding of career progression. CHWs may be interested in building skills within their current role; they may also seek to adopt new leadership roles within the organisation or team or use the job as a stepping stone to further opportunities (Cometto et al., 2018). In-service training, as well as more routine interactions within CHW teams, can build confidence around a current skill set (Ndima et al., 2015). Programme leadership should regularly communicate with CHWs to discuss immediate and longer-term goals, and articulate routes to attaining these goals. On a broader conceptual level, CHWs should also feel that there are adequate opportunities for progression, as these options can serve as motivators (Abdel-All et al., 2019). These considerations are particularly important in places with high levels of job insecurity.

Strengthening systems through increased communication and advocacy

My final recommendation for practice echoes a broader approach for addressing persistent contextual problems. In tandem with the above recommendations, a broader level of systems strengthening would help to facilitate quality improvement and linkages to care. This recommendation stems from my findings that CHW programmes are limited in their capacity to drive health outcomes in the absence of functioning or responsive health systems. It also echoes some current debates in CHW research, including work by Helen Schneider and Uta Lehmann adopting a “community health systems” approach to improving health equity (Schneider & Lehmann, 2016).

From a programmatic perspective, for CHW programmes run by NGOs, this process could involve a pre-planning phase that adopts a structured approach to bring diverse stakeholders together (Cometto et al., 2018). This pre-planning would set terms of reference for the implementation of the programme and create a platform for CHW programme leadership (senior management as well as team supervisors) and local health system leadership to communicate. This starting process and any subsequent engagements should ideally be rigorously documented to assist in ongoing operations as well as setting standards and expectations for if and when programmes go to scale (Naimoli et al., 2015). For CHW programmes that exist as extensions of formal health systems or are already officially embedded within government policies, this process may look different; however, it is still essential to set expectations about how CHWs can fit within existing systems and structures, and how the clients they serve can benefit from the services they require.

This process may further entail creating a clear channel for CHWs and programme leadership or supervisors to advocate for their clients’ needs in health settings. It might also involve providing opportunities for primary health care provider

sensitisation around the preventative potential of CHWs; this sensitivity and accountability to CHWs may be increasing with the promotion of WBOTs but also lagging given deep-seated hierarchies in health systems (Eyles et al., 2015).

Finally, funders and programme staff introducing community-based and community-driven programmes aiming to address inequalities in access or services should acknowledge existing practices, mechanisms, and solutions that are in use, by clients or CHWs themselves. Importantly, programmes may further be strengthened through recognising and integrating these practices into how programmes are run.

Recommendations for research

In addition to identifying overarching contributions and recommendations for practice, I also highlight a number of interesting avenues for further research to enhance and extend the findings of this dissertation. These recommendations include: 1) longitudinal research, 2) the training environment, 3) closer analysis of client-CHW relationships, 4) participatory research, and 5) health geography research.

Longitudinal research

The HCSI, while practical in its “snapshot” form, may be further developed by additional longitudinal research, tracking the course of a client-CHW relationship over time (Laurenzi et al., 2019). A clear longitudinal extension of this HCSI pilot would be to arrange follow-ups with the same client and MM over the course of a number of consecutive visits. This research could happen within Enable or a broader definition of community-based programme. Longitudinal research could further incorporate multiple interviews with the same client to assess how her relationship with her CHW and the programme changes over time. This process could similarly take place with CHWs over

the course of delivering an intervention, rather than at one time point, to gain a more comprehensive, time-sensitive perspective (Busza, Dauya, Bandason, et al., 2018).

The training environment

Similar community-based health programme research could benefit from a closer examination of training, including pre-service, in-service, or both types of sessions. This focus area might include developing and testing additional training modules that embed principles of adult education more deliberately (Simelane et al., 2018). It might also look at research that engages with CHWs and supervisors at regular intervals throughout a longer pre-service training period to understand effective learning strategies and identify gaps from early on. Finally, there may be additional opportunities to integrate training content with the longitudinal research proposed above, as a means to capture fidelity to training on core content over the course of a client-CHW relationship, as well as to training on communication skills.

Closer analysis of client-CHW relationships

Another enhancement to this research could be to explore CHW and client relationships in tandem. While each article in this dissertation focused in on a single data source, the interview data I collected from Enable's clients and MMs about their relationships might be compared and analysed together. New research could also look at dyadic interviewing with CHWs and clients, to encourage them to frame these experiences in conversation with one another (Morgan et al., 2015). While this method may have challenges regarding power dynamics or hesitancy from either participant, it could also present an opportunity to engage CHWs and clients in conversations about their relationship in a neutral space over a number of interviews. Moving one level out

from the client-CHW relationship, supervisors and CHWs could also engage in partnered interviews or discussions to identify important aspects of engagement and support in the workplace. These efforts might be able to influence more routine programming and practice, helping to inform in-service training, for example.

Participatory research

Conducting participatory research with clients and CHWs alike could present valuable insights about how, and where, to improve programme delivery. Existing approaches to community-based participatory research in CHW programmes and maternal and child health have shown promise for creating more equitable spaces for community-provider engagement (Foster et al., 2010; Wallerstein & Duran, 2010), and are seen as a way to democratise the process of scientific inquiry.

This process may include more innovative methods, too (Israel et al., 2012). In the Enable context, for example, mapping support networks in a group setting might be useful for clients or MMs to visualise possible nodes of support, given findings about diverse support needs, and to encourage discussion of strategies for accessing additional services. These support networks may also be important for health-focused programmes seeking to effect behaviour change and understand clients' environments and life circumstances. Additional methods such as illness diaries—which for this health focus area might be recast as infant diaries—or other types of longitudinal narratives might be able to provide a more comprehensive perspective on clients' experiences in non-intrusive ways (Goudge et al., 2009). Effectively improving programming might also rely on engaging with participatory methods among CHWs and supervisors, to identify existing best practices and realistic shifts in goals.

Health geography research

Given the focus on geographical and infrastructural constraints for rurally-based CHW programmes, more geospatial research linked with health-related process data should be initiated and embedded into existing research (Wang, 2020). This includes mapping physical distances, as well as terrain, road networks, service points, and population density (Guagliardo, 2004). These approaches represent a mixed-methods, interdisciplinary means of framing more comprehensive debates about health access, improving outcomes, and allocating resources effectively. Furthermore, specific data about programme areas might present important opportunities for pre-planning as programmes transition to scale, able to provide more comprehensive contextual data to inform key decisions.

Limitations

The limitations of this study were two-fold: methodological and conceptual. Methodologically, data across each of the results chapter were qualitative, and originally collected in isiXhosa before being translated to English and transcribed. The process of translation to another language, as well as the process of transcribing audio-recorded interviews into text, may present barriers to analyses.

Limitations surrounding the audio-recorded home visits are also worth mentioning. As a method, using audio recordings may be less intrusive, but still invites some potential for bias in overlooking other non-verbal cues, or inadvertently encouraging MMs to perform better due to having a “listener.” This method could also be strengthened by continuity of visits, recording sessions with the same client over a longer period of time; however, this was not possible given the time and financial constraints of this study. The HCSI, as a checklist tool to assess these transcripts, has a

number of additional limitations. It was developed in part using skills integrated into the Philani training model and may not be able to be disseminated for other types of programme models without adaptation. While it is generally user-friendly, it still requires a substantial amount of time and effort to use in field-settings, incorporating recording, translation and transcription, coding, and checking. Collapsing some of these processes—for example, by having isiXhosa-speaking (or other target language-speaking) researchers listen and code simultaneously—may remove some of these usability barriers.

Relatedly, my approach to data analysis, had I begun this doctorate now, would have also been slightly different. This approach described above, combining data translation and analysis steps, would also invite researchers who can identify cultural and linguistic nuances to engage with the data more closely through audio analysis. Speaking to some of my reflexivity considerations from Chapter 2, this would simultaneously bring individuals who have worked in transcription and translation into a more analytical role and facilitate knowledge transfer and skills-building, thus reducing power imbalances within a research space. While I engaged my Xhosa colleagues in developing the questionnaire and interpreting some of the translations, I plan to learn and adopt further strategies for co-analysis and more sustained cross-team communication in the next qualitative study I help conceptualise and lead. I believe that the overarching contribution from this dissertation—focusing on a human-centred approach and gathering perspectives from programme recipients and implementers—points to the need to implement practices that contribute to advancing equity and capacity-building within research teams, too.

For the interviews, a longer time frame in the field would have further enabled more robust in-interview procedures, such as more rounds of piloting, transcription and

translation over the course of the interviews to adjust for small errors, and/or follow-up interviews with the same clients. The research assistant who conducted interviews was an experienced interviewer whose prior contact as an external trainer with the MMs was seen as a potential benefit, and the data and depth of each interview showed that MMs were willing to discuss a range of sensitive topics with her. However, it is also possible that certain individuals felt somewhat constrained by this prior contact, which may have affected what they were willing to share.

Conceptually, this dissertation was only able to focus on a certain set of implementation factors. Notably, it does not incorporate in-depth findings related to the supervisory relationship, which means these findings may be overlooking important mechanisms that bolster the quality of services MMs deliver, the support they feel in their job roles, or the quality of relationships they are able to maintain. In this dissertation, I have tended to discuss CHW programmes, and the Enable Programme in particular, in the context of data from MMs and clients, however, I acknowledge that this framing may at times conflate two levels of how the programme operates. Perhaps based on prior contact with the MMs at Enable through team engagements and external trainings, I also may have made certain assumptions about their commitment to the role, or their approach to the programme, in how I analysed data. Overall, these interviews were positive in nature, but this prior experience may have been an external influencing factor.

Process evaluations can also, at times, collect a systematic set of data about visit frequency, content covered, and targets reached, in an effort to contextualise or quantify the findings further. This study, instead, focuses predominantly on how clients and MMs interact, at the delivery site of the intervention, and what takes place in the home visit—and how context shapes what this home visit can deliver for clients. This research could

be bolstered by additional mixed-methods approaches to strengthen the conclusions drawn. Furthermore, research detailing supervision within CHW programmes may be able to provide more insight into how supervision processes shape effective programme delivery and implementation.

Again, as I shared in my Reflections section of Chapter 2 (p. 33), my role and perspective as a white American woman may have influenced my questions, analyses, and conclusions in certain ways. While I believe I have approached this work as neutrally and systematically as possible, this researcher bias and power dynamic inevitably shapes the conclusions that I present here, and the way in which this research was conducted. The team-based nature of the research design and data collection processes was targeted at mitigating some of these biases. My intention for this study and future research is to be explicit in understanding my own position and how it influences my outlook, and identify ways to promote equity and reduce imbalances in the process of knowledge production.

Conclusion

The findings from this study contribute a more comprehensive picture of the processes underpinning the delivery of a CHW programme in rural South Africa. They draw out interpersonal and contextual factors that affect how the programme is delivered, received, and embedded in a larger environment. On a more fundamental level, this work adds to a body of research that has identified ongoing challenges in the scaling up of CHW programmes. In identifying the strengths of the Enable MM programme, and the multi-faceted relationships it promotes and fosters, it also asks the question: is this programme working for everyone? While the data and analyses presented in this dissertation are largely supportive of the CHW model, and illuminate

advantages of using community-based approaches and social franchising to deliver high-quality care for vulnerable populations, they also elicit questions for upcoming research and practice in this field. These questions include grappling with ideas about sustainability at scale; the rights and responsibilities of clients and CHWs; and practices that can enhance the effectiveness of CHW programmes in improving health equity and outcomes for all.

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Appendix A: Published version of Article 1 (Chapter 3)

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RESEARCH ARTICLE



The home visit communication skills inventory: Piloting a tool to measure community health worker fidelity to training in rural South Africa

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Abstract

Community-based home visiting programs using community health workers (CHWs) have become popular modes of delivering health care services, especially in settings where health workers are overburdened and resources are limited. Yet, little is known about the processes that shape effective implementation in low-resource settings, and whether these processes adhere to home visitors' training. This study used the newly-developed Home Visit Communication Skills Inventory (HCSI) to explore the delivery of a CHW program in rural South Africa. Routine home visits from CHWs to their maternal care clients were audio-recorded with consent, and later transcribed and translated into English. The HCSI, devised and piloted using existing frameworks and program-specific training components, consisted of 21 items covering domains related to active listening, active delivery, and active connecting, and was used to score English transcripts of the home visits. The HCSI was used to generate general frequencies and aggregate scores for each CHW. Eighty-four home visits by 14 CHWs showed a diverse application of communication skills. Active listening and active delivery were common, with fewer instances of active connecting observed. Practices disaggregated by CHW showcased varying strengths by an individual. In reviewing visit characteristics, longer average visit duration was significantly correlated with the presence of multiple types of active connecting skills. While technical skills were widely observed, fewer CHWs engaged in more complex "connecting" skills. The HCSI is a feasible, low-cost, and practical way to describe home visit fidelity among CHWs. Audio-based checklists can be used to describe fidelity to a model in the absence of additional supervisory resources.

KEYWORDS

communication skills, checklist development, community health workers (CHWs), home visiting, rural health, South Africa

1 | INTRODUCTION

Community-based home visiting programs are key modes of delivering health care services, especially in settings where facility-

based health workers are overburdened and resources are limited (Tulenko et al., 2013). Much of the evidence promoting home visiting programs have come from studies focused on assessing their impact (Bhutta et al., 2013; Christopher, Le May, Lewin, & Ross, 2011;

Haines et al., 2007; Hill et al., 2014; Lewin et al., 2010). While for the most part impacts have been positive, there have been varied results, in part because the ways in which these programs are implemented can vary tremendously. The evidence supporting home visiting programs has often failed to translate to practical, “real world” effectiveness, especially when these programs are expanded and replicated in new settings. Barriers to this knowledge translation include the lack of human and financial resources to adequately scale programs (Haines et al., 2007), inattention to contextual factors that may limit a program’s acceptability to its beneficiaries (Blacklock et al., 2016), and fidelity to the intended intervention.

Fidelity is a crucial, yet often overlooked, part of implementing home visiting programs (Kim et al., 2015). Fidelity to an intervention relates to both content (is key content delivered as intended?) and structure of delivery (are core practices being enacted as intended?; Dunst, Trivette, & Raab, 2013). The first category presents practitioners and researchers with more clear-cut tools, enabling the measurement of dosage, and content delivered. However, less tangible processes, such as implementer competence, are more difficult to engage, identify, and measure (Tomlinson, Hunt, & Rotheram-Borus, 2018). Implementer competence relates to communication, skills, and abilities that can affect the intended delivery of an intervention (Breitenstein et al., 2010). These factors are likely to be just as important in determining a program’s success as the number of visits completed, or the degree of adherence to a manual (Korfmacher, Green, Spellmann, & Thornburg, 2007; Schodt, Parr, Araujo, & Rubio-Codina, 2015). Nonetheless, measuring dosage and content has up to now proven to be easier, and less expensive, than more thoroughly examining soft implementer skills.

A number of contextual factors highlight the need for more investment in implementer skills, especially in low-resource settings. Evidence from home visiting programs indicates that simply relaying content or delivering instructions is not sufficient to make interventions effective (Brookes, Summers, Thornburg, Ispa, & Lane, 2006). Implementer competencies such as manner of engagement, body language, and communicative style can determine whether or not a client wants to begin or continue a clinical relationship (Breitenstein et al., 2010). Often, community health workers (CHWs) from low-resource settings require more training in these skills. While they may have local buy-in and be culturally similar to their clients (Kilpatrick, Cheers, Gilles, & Taylor, 2009), they also tend to be lay workers with limited employment, education, and preservice training experience (Glenton et al., 2013; Kemp & Henderson, 2012). Supportive supervision, which can mitigate these shortcomings, is often not possible in programs that are under-resourced and geographically dispersed. Thus, for CHWs to deliver interventions with fidelity, they ideally require a core set of competencies and opportunities to build and develop individual skills for their role, as well as an organizational environment conducive to nurturing these skills. Limitations in funding, supervision, and geographical and social context can act as barriers to quality in implementation.

It is important to consider means to extract key implementer skills and find simple, yet valuable ways to measure these skills and how they

may affect the delivery of an intervention. Motivational interviewing and communication analysis literature, which includes analysis of patient–clinician interactions (Kilian, Swartz, & Chiliza, 2015; Roter & Hall, 2006), can provide a template for measuring softer implementer skills, such as communication style and interpersonal competencies. The available evidence emphasizes creating solidarity or establishing an emotional bond; using different types of questions or speech prompts to gather information; providing information through facilitation, instruction, or direction; responding to information given as well as to feelings or concerns; and a focus on reciprocity or cooperation in making decisions about health behaviors (King & Hoppe, 2013; Roter, 2000b). To capture these factors, checklists can present more streamlined ways of translating findings to operational contexts; they have also been used in process research as well as health care settings to assess quality, standardize delivery, and observe fidelity (Dorsey et al., 2018). However, few checklists are present in community-based care settings, or as related to implementer skills.

In this study, we considered the most effective and practical way to capture implementer (CHW) competence related to a specific set of communication strategies. Communication strategies are one skill set that training may cover, yet little research has been done on how well this training translates into a home visiting setting (Roter & Hall, 2006). We piloted a communication checklist, which we entitled the Home Visit Communication Skills Inventory (HCSI), to explore the delivery of a CHW program in rural South Africa. This descriptive study aimed to capture communication skills in a home visit set as part of a larger study about CHW fidelity to a home-based maternal and child health intervention. What happens as CHWs move from training to delivery, and do we observe CHWs implementing core strategies from training on communication and rapport-building in the context of the home visit?

1.1 | The model and context

The Enable program is a rurally based home visiting intervention, established as the first “social franchise” of the Philani Mentor Mother model. “Social franchising” involves similar concepts to commercial franchising, where a model is taken to a new setting under new management, but aims to accomplish social ends, instead of seeking profit. In the Mentor Mother model, local mothers are identified through informal networks such as community leaders or village/neighborhood meetings, then selected and trained to deliver a home-visiting intervention (Le Roux, 2015). The program specifically looks for “positive deviants”—mothers who have been able to rise above adversity to raise healthy children—to provide support and education to their peers (Marsh, Schroeder, Dearden, Sternin, & Sternin, 2004). Master trainers conduct a 6-week training course for Mentor Mothers (MMs), which includes didactic lessons on health information, practical skills about establishing relationships and connecting to clients, and role-play and problem-solving practice sessions. Following this training, trainees complete a final examination. Performance during training and on the examination, as well as logistical considerations such as where each woman resides,

determine which of the trainees are ultimately selected as MMs. The selected MMs recruit pregnant mothers from their own village catchment areas and conduct routine home visits to educate and support clients through pregnancy, delivery, and their infants' first years of life. The program's key focus areas include maternal and infant wellbeing, child nutrition, immunization, HIV/AIDS prevention and treatment, and access to social and health services. In addition to supporting pregnant and recently-delivered women, MMs also identify and visit undernourished children and clients with chronic conditions requiring home-based care.

2 | METHODS

Stellenbosch University's Health Research Ethics Committee granted ethical approval to collect home visit data (N16/05/062).

2.1 | Setting

The Enable program is based in the Nyandeni Municipality, in the O.R. Tambo district of South Africa's Eastern Cape Province. Preparations for the Enable social franchise began in early 2016. Training of potential MMs took place in May and June, and the MMs selected for employment began recruiting clients in July 2016. In addition to 14 MMs each operating in their own area, the original supervision team consisted of two supervisors (one with a clinical background and the other with operational roles), and one program coordinator.

Nyandeni was selected for its poor health outcomes and access. Many of the critical health considerations facing South Africa's urban population, for which the Philani MM model was originally developed, are intensified in deeply rural settings like Nyandeni, where infrastructure is poor, options for transport to health centers are limited, and economic and employment opportunities are scarce (Massyn, Padarath, Peer, & Day, 2017). As such, the social franchise approach and the translation of a model from one setting to another presents an opportunity to consider fidelity in implementation and process.

2.2 | Data collection procedure

This study used audio recordings of routine home visits to pregnant and recently-delivered clients of the Enable program. The data for this study were collected during a sample of routine home visits conducted by Enable MMs during visits with pregnant clients and new mothers and their infants. An independent isiXhosa-speaking research assistant accompanied each MM on a randomly selected day to all of her planned perinatal and infant visits, to obtain consent to audio-record the visit. No supervisors were present for these specific visits. We employed an independent research assistant to reduce risk of bias or of jeopardizing the client-MM relationship, separating the MMs from the data collection process as much as possible. MMs were notified 1–2 days prior that they would be

accompanied. Before the routine visit began, the research assistant sat one-on-one with the client to review an informed consent form that contained simple language recommended by the ethics review board. Our method of translation included having all consent forms translated into isiXhosa by a research team member and quality-checked by a senior team member before use in the field. During and after review, the research assistant gave the client the opportunity to ask questions or to refuse to participate. If the client consented, the research assistant would start a new recording on a handheld audio recorder and exit the household, and the MM would enter.

Recordings began in January 2017, and were staggered by MM, with some MMs revisited to capture additional recordings, until February 2018. Additional recordings were sought to ensure a roughly equal number of visits for each MM. Informed consent forms were signed by all participants; audio recordings were downloaded and removed from the recorder on the same day as collection and kept in a secure location. Two isiXhosa-speaking transcribers were responsible for simultaneous transcription and translation from isiXhosa to English; approximately 25% of transcripts were reviewed by a senior isiXhosa-speaking team member for quality control purposes. All transcripts were anonymized using a participant identifier.

2.3 | Developing the Home Visit Communication Skills Inventory (HCSI)

To analyze key themes across transcripts of these audio-recorded home visits, we developed a checklist, the HCSI. We decided to use a checklist to capture the presence of key skills, in lieu of coding each phrase in the transcripts. The HCSI was developed using a combination of reported best practices from similar research, program-specific guidelines, and iterative additions. First, existing frameworks and measures from client-provider communication research were surveyed through literature searches including keywords such as "patient-provider communication," "client-provider-communication," and "physician-client communication" (Abdel-Tawab & Roter, 2002; King & Hoppe, 2013; Roter, 2000b; Roter & Hall, 2006; Watermeyer & Penn, 2009). Related work evaluating home visit program quality was also reviewed (Peterson, Luze, Eshbaugh, Jeon, & Kantz, 2007; Roggman et al., 2016). Further literature was identified from these initial searches.

Second, in-depth notes were made from the Philani training manual's module on communication, which teaches specific skills for communication and broader strategies for relationship-building within the context of the home visit (Philani Maternal Child Health & Nutrition Trust, 2016). Six key questions about MM skills and behaviors during the visit were formulated, based on the core components of the training chapter. These questions guided the design of a draft checklist, synthesizing the reviewed communication skills, and adopting "best practice" frameworks to reflect specific features of the training. CL devised an initial checklist of 17 items, which was checked by SS and MT. During a pilot stage, approximately 20 transcripts were read and coded using this draft checklist, after which minor iterative changes were made to reflect the

TABLE 1 Home visitor communication skills inventor

Domain	Communication strategies, guided by key questions
Active listening	<p>Does the mentor mother employ each of the following active listening skills?</p> <p>Ask for clarification^a</p> <p>Gather information^b</p> <p>Reflect content/information given^a</p> <p>Reflect feelings/concerns^b</p> <p>Does the MM encourage dialog by asking open questions, and engaging “tell me more” techniques or rhetorical devices?</p> <p>Asking open questions consistently (at least three examples)^b</p> <p>“Tell me more” techniques^a</p>
Active delivery	<p>Does the MM share relevant information that addresses the client’s situation, and/or reference prior visits to build on knowledge?</p> <p>Relevant new information (at least three examples)^a</p> <p>Information retention (checking on information retained from a prior visit)^b</p> <p>Visit continuity (regarding knowledge, health education imparted previously)^c</p> <p>Does the MM ensure that the client understands her, and understands the choices she has to make?</p> <p>Ensuring comprehension^b</p> <p>Soliciting questions^a</p> <p>Using questions to probe understanding^a</p> <p>Does the MM counsel the client in a way that suggests, rather than dictates or directs—meaning that the client has room to make her own health decisions?</p> <p>Clear “suggest” statements present, more than directives^a</p>
Active connecting	<p>Does the MM show a range of diverse examples of connecting to the client?</p> <p>Empathy and/or understanding^a</p> <p>Recognize, praise, or affirm^a</p> <p>Nonjudgmental attitude^a</p> <p>Articulating confidentiality^a</p> <p>Articulating trust in the relationship^b</p> <p>Sharing similar experiences/observations^c</p> <p>Other rapport-building evident^b</p> <p>Visit continuity (regarding connecting again)^c</p>

Note: Items have been drawn from three main sources (mentioned below) and some concepts have been rephrased for clarity and applicability.

^aPhilani Training Manual, 2016.

^bRoter Interaction Analysis System framework.

^cSharing similar experiences/observations.

communication skills observed, resulting in the final HCSI, comprising 21 items (Table 1). Changes included the addition of two new categories and the combination/division of existing categories.

2.4 | Checklist scoring and analysis

Transcripts were organized in ATLAS.ti software, where codes were applied that matched the 21 HCSI items. A primary coder (CL) reviewed each transcript against the HCSI items and coded a given phrase or exchange as reflecting this communication skill. After the transcript was reviewed twice by CL, the strategies coded were entered into a database using a 1 (present) or 0 (absent). A secondary coder (SG) trained on the HCSI coded 10% of transcripts and discussed scores with CL for reliability. In cases of disagreement, both coders met to discuss and resolve discrepancies; however, overall, there were very few instances where coders disagreed on the presence of an element (15/200 disagreements, 7.5%).

The analysis was conducted across two levels: first, general frequencies of observed communication strategies were recorded across all MMs. These frequencies were organized individually, and

also into the following three domains: active listening, active delivery, and active connecting. These domains were devised as a way to group like skills thematically: listening, delivery, and connecting were chosen as three overall strategies that encompassed key skills for MM-client engagement, and that necessitated MMs taking an active role in driving the interaction. Active listening is commonly understood as having skills to concentrate, comprehend, and adequately respond to an individual over the course of a conversation or counseling session. Active delivery was conceptualized as a further step beyond this skill: selecting a response to the client’s individual situation or needs, and following through on the information shared with that client to facilitate understanding, retention, and confidence on the part of the client. Active connecting, as a third overarching domain, was seen as additional skills related to fostering a relationship with the client and utilizing strategies to build rapport in diverse ways.

Second, strategies were disaggregated by MM to observe variation among MMs and by domain. For each MM at each visit, items within each domain were summed (how many strategies observed of the total available), and an average of these scores was taken. These averages were then converted to proportions.

3 | RESULTS

3.1 | Descriptive information

3.1.1 | Home visit recordings

Table 2 shows a summary of descriptive information. In total, 84 home visits were recorded, transcribed and coded. While each of these 84 transcripts reflected separate home visit sessions, five clients were recorded twice ($n = 79$ clients). The majority of clients were pregnant. Visit duration ranged from a quick check-in visit of three and a half minutes to a 34-min session; the recorded visits averaged just over 16 min.

3.1.2 | Mentor mothers

All 14 MMs were accompanied for a subsample of their visits with different clients to be recorded. On average, six visits per MM were recorded. To obtain a substantive number of audio recordings across all MMs, each MM was accompanied on either one or two full days to all of their daily visits.

3.1.3 | Clients

Clients ($n = 79$) were a mix of first-time mothers and experienced mothers; just over one-third of clients sampled were expecting or had delivered their first child (35.7%), whereas seven clients (8.3%) already had four or more children before entering the program. Eight

clients (9.5%) were 18 years or under at the time of recruitment into the program. While the duration of the relationship between MM and client ranged from one prior visit to 34 visits, the average number of visits before our recording session was 11.

3.2 | Observed practices

The communication practices observed in-home visit sessions are reflected using illustrative examples, as well as frequencies of HCSI observations by cohort and by individual MM, shown in Figure 1.

3.2.1 | Active listening

Across recordings, most visits showed evidence of gathering information, and asking open questions (e.g., inquiring about feeding practices and follow-up dates), as well as probing clients to give more context about clinic visits or ongoing health issues. Most visits also gave evidence of the MM reflecting the information or content she was given. These instances included reflecting information given verbally, information gathered from observing the child, and information gathered from reviewing health records such as the mother's maternity card or the infant's Road to Health Card (e.g., "Since it's written here on your card, it shows that you are HIV-negative").

The practice of asking for clarification was also present in over 80% of visits, for example, the MM asking, and "tell me more" techniques, which might constitute a MM prompting, "Mhmm...", or "What else?" were also observed across nearly 70% of visits. While reflecting content and information was common, reflecting feelings and/or concerns of the client was less common.

3.2.2 | Active delivery

Nearly all visits showed at least three instances of the MM delivering information relevant to the client about her own health or pregnancy, as well as preventative health advice for her baby's health. Ensuring comprehension and using suggestive (rather than a directive) language were also common practices, present in over 80% of visits. Often MMs would conclude with "You see?" or "Do you understand?", but sometimes they used demonstrations or visual aids to ensure comprehension, such as the child's growth chart attached to the case file:

MM: [She] was on 3.4 kg, now on 3.7 kg, you see on this chart since there are these black lines, then there are these ones below, the baby's weight needs to be here (pointing), inside, if it is here, that means the baby's weight doesn't correspond with her age, maybe she had...flu or stomachache or whatever. So yours is inside this thing, she is on this thing (pointing) here.

TABLE 2 Descriptive information about the home visit recordings

Session information	N	Mean (M), standard deviation (SD), range
Audio-recorded home visits sessions coded	84	
Home visits during client pregnancy	53	
Home visits after client delivery (with child)	31	
Length of visits (mm:ss)		M = 16:13 SD = 7:15 Range = 3:30–33:54
Client information	79	
Age of clients		M = 25.72 SD = 6.23 Range = 15–41
Clients who are first-time mothers	30	
Number of previous children, mean		M = 1.42 SD = 1.57 Range = 0–7
Mentor Mother information	14	
Recorded visits per mentor mother		M = 6 SD = 1.52 Range = 3–8

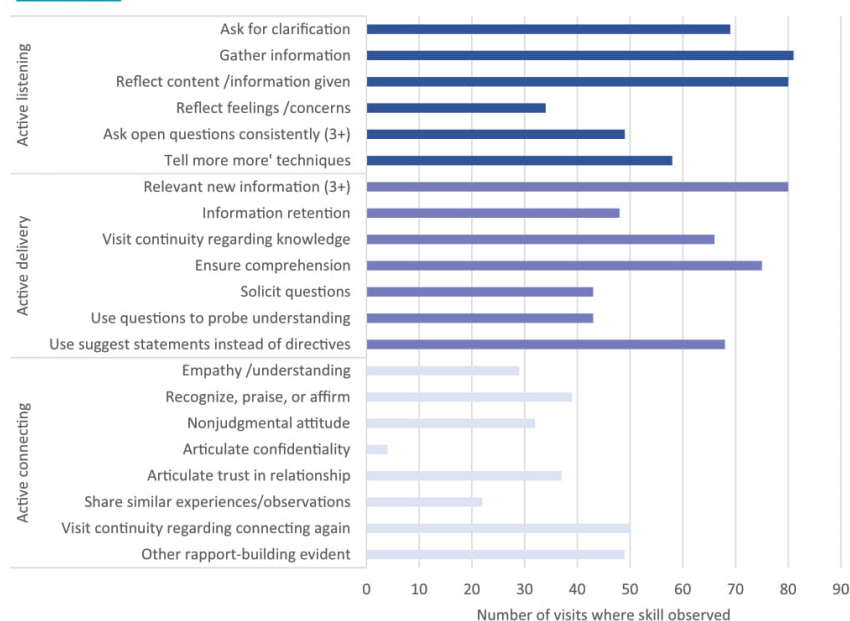


FIGURE 1 Frequencies of communication strategies observed in Home Visit Communication Skills Inventory ($n = 84$ visits), domains coded by color. [Color figure can be viewed at [wileyonlinelibrary.com](https://onlinelibrary.wiley.com)]

Suggestive statements used key words such as *emphasize*, *suggest*, *encourage*, or other words conveying importance, without clearly instructing or directing the client: "because us, as MMs, we do not encourage [baby cereal]." At times, these phrases were also used to give the client guidance about how to broach the topic with their partner, such as insisting on using condoms during sex:

The condom protects you and protects the baby...so now you need to show that you will be the caring parent, you will be the responsible parent from now, if you say something goes this way, say it to your partner that "it is like this," also by the time you [are] breastfeeding, even though we are not there yet, [a] condom needs to be used.

A majority of visits also showed the MM following up on a health problem or behavior discussed in prior visits, ensuring a sense of continuity in health education.

Over half of visits included checking on information retention from prior visits, soliciting questions, and using questions to probe understanding, such as: "Do you still remember your date to go for a checkup at [the hospital]?" When MMs solicited questions, they would often finish explaining a health issue by saying, "Is there anything you don't understand that you want to ask?" Using questions to probe understanding encompassed more deliberate examples, or using a client's words to invite more explanation, such as, "why [are] you saying [your] baby doesn't get full with breast milk?"

3.2.3 | Active connecting

Discussing visit continuity regarding visiting again was the most commonly observed active connecting skill (59.5%). Examples of visit continuity included general statements, such as, "I'm going to visit you often, visiting you often as you are about to give birth, weekly, chatting and advising each other about constructive things." They also included more specific scheduling by day or date, or conveying a sense of MM availability: "When there is something that you don't understand, you just call me, I am easy to reach. You would ask what is happening, then I would tell you what to do." A high proportion of visits demonstrated MMs employing similar rapport-building (connecting) techniques. Sharing similar experiences was less commonly observed, but used to establish rapport as well, such as a MM instructing her client to communicate with her after a clinic visit, "Yes, because—there is that thing of going to [the clinic] and not receiving immunizations."

Nearly half of the visits (46.4%) showed evidence of the MM recognizing, praising, or affirming the client. Often these phrases included a compliment about the baby, but sometimes comprised other affirmations: "You are doing an important thing, sis, it is important to test and to know your [HIV] status." Articulating trust in the relationship was also present in nearly half of the sessions, in which the MM might indicate a shared commitment: "as we come here often, we want to raise this child together." Discussing trust also encompassed requests for openness by the MM:

A Mentor Mother then, as I'm visiting here, is a person to look after you and also when there is something that you don't understand, you must ask and tell [me] that I have this thing, this problem, I have this thing that I don't understand and ask. You are allowed to ask anything to a Mentor Mother without hiding anything.

Fewer MMs were observed clearly articulating confidentiality by explicitly stating that they would not share the information covered in the sessions. One of the few examples included the following reassurance: "Every problem that you have... I don't share it with anyone, I don't go around talking about it, I don't share it anywhere, even at home." Empathy and understanding, and nonjudgmental statements were also less commonly employed. In a nonjudgmental statement, the MM might convey information with a certain sensitivity: "The reason to check this virus is for in case it happens, I am not saying [it] is, if it can happen, that there is to try and protect the baby on time."

3.3 | Observed practices, by Mentor Mother

The observed practices disaggregated by MM are shown in Figure 2, and indicate significant variations by MM. All MMs had higher scores in active listening and delivery than they did in the active connecting domain; however, some MMs showed a higher proportion of active listening skills, whereas others scored higher on active delivery skills. Within specific practices, there was also considerable variation. Active connecting skills were less commonly observed and applied in different combinations. On average, MMs exhibited just over three diverse types of active connecting skills per visit. Just over one-third of visits (34.5%) employed four, five, or six types of these skills, and 12 visits (14.3%) employed one or none.

3.4 | Variation in mentor mother performance

To add a further dimension to these findings, we looked at the age, education level, and average visit duration, captured by the length of the audio recording, for each MM. Table 3 shows these variables together with MMs' performance across domains, and Table 4 presents them in a correlation matrix. These findings indicate longer average visit duration was correlated with the presence of multiple types of active connecting skills ($r = 0.81$; $p < .001$). No other variables were highly correlated.

4 | DISCUSSION

This analysis is the first of its kind to document communication practices in a rural home visiting program, and specifically in a low-resource, community-based setting. There was high fidelity of best practices for communication observed in the visits, especially with regard to active listening and delivery. MMs used a variety of techniques to gather and reflect content from their clients; they consistently delivered relevant information, and engaged their clients through dialogue, ensuring their own understanding as well as verifying clients' understanding. Core intervention skills taught in training and supported through supervisory structures center on the ability of the MM to assess her client's situation and deliver a relevant intervention. These skills were widely observed.

As an opportunity to pilot a newly devised communication checklist, the HCSI, this study also reflects key areas for further application. Over 80% of home visits showed evidence of "suggestive" language, instead of didactic, directive statements, to equip the client with the knowledge and at the same time give her space to make her own health decisions. While this figure is high, it is important to recognize that collaborative interactions encouraging client-agency are central to the MM model, and should be aspects of every visit. Our

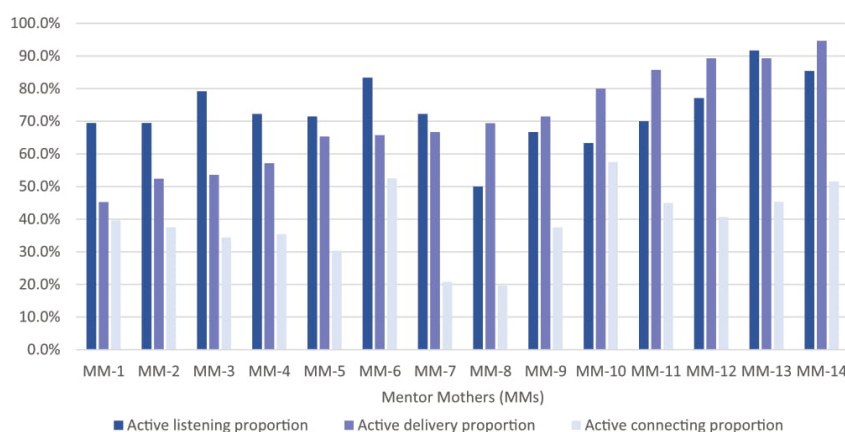


FIGURE 2 Performance by mentor mother across domains, by percentage. [Color figure can be viewed at [wileyonlinelibrary.com](https://onlinelibrary.wiley.com)]

TABLE 3 Mentor Mother variables and communication domains

MM	Age at job start date	Highest education completed (grade)	Average visit duration (mm:ss)	Active listening (proportion)	Active delivery (proportion)	Active connecting (proportion)
1	29.83	12	07:36	0.694	0.452	0.396
2	33.42	11	17:40	0.694	0.524	0.375
3	38.83	12	16:53	0.792	0.536	0.344
4	31.67	12	10:16	0.722	0.571	0.354
5	22.92	11	13:04	0.714	0.653	0.304
6	25.67	12	22:31	0.833	0.657	0.525
7	45.67	10	10:42	0.722	0.667	0.208
8	41.67	11	8:51	0.500	0.694	0.196
9	29.33	12	15:09	0.667	0.714	0.375
10	34.17	11	29:09	0.633	0.800	0.575
11	50.17	10	14:25	0.700	0.857	0.450
12	38.42	12	17:35	0.771	0.893	0.406
13	31.67	12	19:39	0.917	0.893	0.453
14	34.67	12	23:41	0.854	0.946	0.516

Note: Proportions shown are out of a total of 1. For each Mentor Mother at each visit, the number of strategies observed of the total available was summed, and an average of these scores was taken across all visits. These were subsequently converted to proportions.

initial exploration indicates that this method of observation can be used to comprehensively highlight the strengths and limitations of implementer skills in communication and program delivery.

While active listening and active delivery were consistently well-documented, active connecting was less so. Our findings indicate that, beyond core informational and conversational strategies, more complex rhetorical strategies were not readily observed across all MMs, or within all visits. Soliciting questions, using questions to probe understanding, reflecting feelings and concerns, and active connecting skills were unevenly distributed across visits and MMs. Regarding active connecting skills, most MMs spoke about continuing visits and demonstrated general rapport-building; however, fewer explicitly articulated confidentiality, empathic statements, or offered anecdotes or similar experiences to relate to clients.

A necessary next step is distilling whether or not these less-frequently observed practices are "central" features of the intervention, or if their presence adds to the value of the intervention. Existing evidence shows that communication practices and styles form a crucial basis for building trusting clinical relationships, which

can affect health service delivery and access. In periurban settings in South Africa, mistrust between clients and health providers and unclear expectations negatively influenced otherwise accessible and affordable care (Scheffler, Visagie, & Schneider, 2015). Within home visiting programs, in particular, research has shown that relationship quality has a significant bearing on participant experience of the program (Bain, Dawson, Esterhuizen, Frost, & Pininski, 2017). Furthermore, home visitor conscientiousness and home visitor–client compatibility have been found to strongly influence relationship quality and uptake (Brookes et al., 2006). While the contexts in which health-focused interventions are implemented vary widely, the literature suggests that certain core principles of good communication between provider and recipient are standard across settings (Rollnick, Miller, Butler, & Aloia, 2008; Roter, 2000a). The HCSI may be overly inclusive—for example, not every visit may require an articulation of confidentiality. However, these data emphasize the importance of selecting core communication strategies to train and support MMs to employ to ensure a high-fidelity, standard set of expectations.

TABLE 4 Correlation between communication domains and Mentor Mother information

	Age	Education	Average visit duration	Active listening	Active delivery	Active connecting
Age	1.00					
Education	−0.61	1.00				
Average visit duration	−0.18	0.18	1.00			
Active listening	−0.24	0.45	0.40	1.00		
Active delivery	0.27	−0.06	0.52*	0.31	1.00	
Active connecting	−0.27	0.34	0.81**	0.47	0.42	1.00

** $p < .001$.

* $p = .05$.

There are a few possible reasons for our finding that active connecting skills were less commonly employed. In examining variation between MMs, different personal styles predominated. Some MMs may master these social skills naturally, whereas others struggle. Individual characteristics, diverse personalities, and differential motivation must be accounted for in interventions like Enable that rely so heavily on interpersonal engagement and trust. There is also some evidence indicating that maintaining professional boundaries can be a challenge for community-based health workers, who are part of the local community yet are set apart through their training and employment (Kemp & Henderson, 2012). Future work with this sample will explore these challenges in a more nuanced way.

Furthermore, MMs may decide, or be asked by supervisors, to prioritize content over communication style, especially when they have other clients to visit. This decision might lead to the MM covering content in clear, explicit ways to ensure knowledge transfer and efficiency—while simultaneously undervaluing skills related to active connecting that might facilitate relationship building, as these skills are less quantifiable. Research about empathic communication in clinical and therapeutic relationships finds that building relationships requires “emotional labor” on the part of the practitioner, which is essential but takes time and effort to cultivate (Larson & Yao, 2005); thus, this observation may be a function of time and workload.

This last point speaks directly to an additional finding of ours that MMs whose average observed visits were longer were also those with higher average scores on active connecting skills. While a range of factors might predict higher scores on active connecting skills—including communication fluency, closeness with the client, and command of intervention content—it is notable that conducting longer visits may encourage MMs to develop and engage a wider range of such interpersonal skills. Longer visits may also be a sign of stronger relationships, where MMs may be inclined to spend a longer time with particular clients. It is important to recognize, however, that long visits may not always be possible, and more work is needed to understand barriers to connecting with clients among CHWs. Upcoming analyses from this project will reflect on how MMs articulate in their own words the process of connecting to clients and building relationships, which may not be fully captured in these visit recordings. Furthermore, more work is needed to ascertain the effect of these softer skillsets on client behavior change and intended health outcomes.

4.1 | Implications for practice

The findings from this checklist analysis, across the MMs, observed, show strengths in skills that are easy to convey in a training set—such as using questions to gather information—and shortcomings in less tangible skills. Two core areas that might be most directly served by these findings are training and supervision. Adhering to a traditional, didactic training format has been shown to inhibit

critical thinking skills and learning (Glenton et al., 2013). Supervision strategies must be sensitive and responsive to differences in the dosage, quality, and style of support given (Rotheram-Fuller et al., 2017). As such, extra opportunities for training and support, as well as differential support, should ideally be accessible and built into program models. It is evident that a number of this program's MMs struggled with some of the more complex interpersonal skills on which they were assessed; improving fluency in delivery might most easily happen through initial and/or ongoing training (Duthie, Hahn, Philippi, & Sanchez, 2012). Employing the HCSI in a training setting—as a means of evaluating skills learned or structuring communication-based sessions—may be practical and valuable. The HCSI may also offer opportunities for supervisors to tailor feedback, or for funders to monitor program implementation around skills translation and use.

The Enable program has adapted more hands-on supportive supervision strategies for MMs whose case folders show problems with delivering intervention content, pairing them with high-performing colleagues who can provide guidance and support. However, Enable and other programs might benefit from more closely examining implementer competence in action, and by adjusting ongoing training and supervision efforts to speak to specific, measurable needs in this area. In considering ways to increase fidelity, it is also important for program models to set up realistic expectations for CHWs that accomplish program goals while also addressing client needs. While a command of intervention content is key, implementers' communication skills have a central role in how clients respond to and engage with an intervention.

4.2 | A practical method of data collection

The method we piloted also has implications for use in other community settings. Client-home visitor interactions have been assessed by directly observing home visits (Peterson et al., 2007), as well as coding video observations (Roggman et al., 2016). However, few studies from low- and middle-income countries have employed these kinds of systematic methods in-home visit settings, in part due to logistical barriers. Our decision to use audio recordings addressed some of these concerns; using a mode of data capture that was portable and unobtrusive was essential, and we were able to smoothly integrate our data collection efforts with the typical delivery of the intervention. Although audio recordings do have some disadvantages, for our purposes they were a feasible way to investigate what took place in the home setting (Brownson, 2017). Client-provider communication has been more widely documented and analyzed in clinical settings in both high-income (George, Manuel, Gandy-Guedes, McCray, & Negatu, 2016) and low-income country settings (Abdel-Tawab & Roter, 2002; Jennings, Yebadokpo, Affo, Agbogbe, & Tankoano, 2011; Kilian et al., 2015; Kim, Kols, Mwarogo, & Awasum, 2000; Watermeyer & Penn, 2009). However, our research shows that client-provider communication skills can be

measured in programmatic settings at the community level, where health-related consultations may exist outside of a traditional clinical setting due to resource constraints and overburdened health systems.

4.3 | Limitations

It is important to note some limitations of this analysis. As these home visit recordings are “snapshots” of the long-term client-MM relationship—taken at a particular place in time, and not observing the client-MM interaction in its entirety—it is not possible to ascertain case history or a full sense of the relationship's continuity beyond the sampled sessions. The longevity of a relationship may contribute to the building of trust and improve communication, and we recognize the potential for more contributing factors that may affect our findings, and that could be added to future iterations of this work. There is also the potential for desirability bias if the MM decides to perform differently or better than she usually would due to an external presence; however, we aimed for our method of observation to be as discreet as possible (Breitenstein et al., 2010). Our use of audio transcripts instead of video recordings, selected for the reasons detailed above, nonetheless glosses over nonverbal communication cues that might invite a different perspective on the relationship or communication skills employed. Using transcripts also poses a complicating factor for working across a language barrier; even for coders who are familiar with Xhosa culture, and who consulted Xhosa colleagues for further questions or clarifications about meaning and translation, there are still potential limits to how conversation is phrased, a topic is framed, or an exchange understood (Xian, 2008). An upcoming replication of the HCSI plans to utilize Xhosa-speaking research assistants to complete the checklist using audio recordings of home visits that will then be quality-checked, reducing the resources required for transcriptions and translations. Finally, although we developed the HCSI based on “best practices” of communication and program-specific training skills, it is possible that other cultural, social, or contextual realities may influence communication styles. Further iterations of the HCSI might solicit perspectives from supervisors and CHWs to integrate their views or to tailor this checklist to suit programmatic needs more specifically. Nevertheless, this analysis establishes important formative work in the development of a checklist for analyzing communication strategies and affirms the viability of more granular, detailed modes of implementation research at a household level.

5 | CONCLUSION

Home visit settings, while often overlooked, are important sites of program delivery, especially as community health programs expand. The findings presented here from the newly-piloted HCSI offer novel insights for researchers and practitioners alike about how to approach monitoring and fidelity in these settings, and how capturing communication strategies can be a specific and measurable way to gauge success in program delivery at a more detailed level.

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CONFLICT OF INTERESTS

The authors declare that there are no conflicts of interest.

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Appendix B: Published version of Article 4 (Chapter 6)

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How do pregnant women and new mothers navigate and respond to challenges in accessing health care? Perspectives from rural South Africa

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Patient responses

ABSTRACT

Women in low- and middle-income countries and in contexts characterized by inequality face various interpersonal and structural barriers when accessing formal maternal and child health (MCH) services. These barriers persist even in contexts where programs to increase access to services, such as community health worker (CHW) interventions, have been implemented. However, while barriers to accessing care have been extensively documented, less is known about the diverse ways that women respond to, and navigate, these situations. This study explores strategies pregnant women and new mothers use to navigate and respond to health care barriers in a rural district in the Eastern Cape, South Africa. Twenty-six pregnant or recently delivered clients of the Enable Mentor Mother program were interviewed about their experiences of accessing formal MCH services. Interviews were conducted between February–March 2018 by an experienced isiXhosa-speaking research assistant, translated and transcribed into English, with transcripts coded and organized by themes using ATLAS.ti software. Facing resource shortages, inconsistent communication, and long travel times to clinics, participants employed diverse, innovative strategies to navigate interpersonal and structural barriers to care. While some participants chose to respond to barriers more passively—citing endurance and acceptance as practices of health system engagement—those participants who focused more on active responses tended to leverage their education, existing relationships, and available community resources to overcome barriers. Nevertheless, most participants described feelings of frustration and dejection. While CHW interventions may alleviate some of the burdens facing fragile health care systems in these contexts, these programs still rely on an underlying infrastructure of care that primary health care clinics and hospitals should be providing. Future programming should work in tandem with formal health systems and should support staff to improve quality of care provided to pregnant women, new mothers, and their infants to prioritize their health at a time of vulnerability.

1. Introduction

The perinatal period is a time of vulnerability for women and their infants that requires comprehensive, attentive health care to protect against risks to maternal and infant morbidity and mortality (Graham et al., 2016). Maternal and infant wellbeing is as much an individual as it is a societal imperative; the ability to seek and receive adequate health care during this life stage is central to promoting healthy development and enabling women and their families to flourish (Stenberg et al., 2014). Recently, global priorities have aligned to advocate for mothers and children during this critical time; the Nurturing Care

Framework (Organization, 2018a), Sustainable Development Goals (Le Blanc, 2015), and drive for Universal Health Care (Ji and Chen, 2016) all contain provisions for improving outcomes for maternal and neonatal populations, especially in low-income settings. However, the poorest, most marginalized women often have negative experiences accessing health services, with health inequities impeding access to quality care (Finlayson and Downe, 2013).

Pregnant women and new mothers in low- and middle-income countries (LMICs) face significant barriers to accessing care, in both individual and structural domains, and may struggle to respond to these barriers in effective ways (Guliani et al., 2013; Langlois et al., 2015). On

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an individual level, health education and influences of social and family networks may drive how, when, and with what frequency pregnant women seek care (Binder-Finnema et al., 2015; Kifle et al., 2017; Munguambe et al., 2016; Scheffler et al., 2015). Interpersonal interactions also shape individual experiences of care, for example, how women are regarded and treated by health providers. A systematic review of interactions with maternal health care providers in LMICs, including doctors and nurses, found that negative attitudes and experiences outweighed positive ones and adversely affected patients' wellbeing and willingness to seek care (Mannava et al., 2015). Structural factors, such as infrastructure, transport affordability and availability, sufficient resources and medical supplies, and household vulnerability can also determine whether women are able to access care, and what these experiences are like (Abrahams et al., 2001; Puett et al., 2015). Women have highlighted the importance of structural factors in shaping their satisfaction with maternal and child health (MCH) care (Srivastava et al., 2015).

For pregnant women and new mothers living in remote, rural settings, these challenges can be heightened. At an interpersonal level, the quality of care received at rural health facilities may be poor. Rural health providers have reported demotivation, dissatisfaction with rural postings, and high stress about resource limitations—resulting at times in what they acknowledge as poor treatment of patients (Melberg et al., 2016; Prytherch et al., 2013; Thi Hoai Thu et al., 2015). From patients' perspectives, a lack of mutual trust and experiences of mistreatment and abuse during health visits, including delivery, create a similar sense of dissatisfaction with services and reduce motivation to seek care, especially amongst the most vulnerable women (Adatara et al., 2019; Bohren et al., 2019). Structural challenges also persist. A study in rural Ghana highlighted difficulties that women faced in obtaining vehicular transport for MCH care, in large part due to location and poor road networks, leading them to opt for less safe transport or care options (Atuoye et al., 2015). In Liberia, increases in distance from a health care facility were found to have a direct, negative relationship with uptake of MCH care-seeking, predicting varying levels of engagement by rural-based women (Kenny et al., 2015).

1.1. Responding to barriers to care

While these diverse challenges to seeking and receiving maternal health care have been well documented across LMIC settings, knowledge about responses to these barriers is limited. Some community-based efforts, such as women's groups, have shown promise in building capacity and sharing information (Morrison et al., 2010), and pairing savings initiatives with health education and social support (Shaikh et al., 2017). Community loan funds to facilitate maternity transport have also been found to have positive effects on facility-based deliveries, emergency access to care, and general uptake of health services (Ekirapa-Kiracho et al., 2017; Nwolise et al., 2014). On a more widespread scale, community health worker (CHW) programs may be able to improve linkages to care through educating and empowering clients and establishing communication channels and referrals systems (Lewin et al., 2010).

However, there is less evidence on how women individually navigate these complex multi-level barriers to accessing health care, at both interpersonal and structural levels. In settings where gender roles are clearly defined, or where men are working away from their homes, women alone may bear a greater responsibility for childcare, which includes accessing health services during pregnancy and following birth (Bougangue and Ling, 2017). The individual perspectives of these women can provide important insights into how pregnant women and new mothers experience the process of accessing care, and how their right to health care is being met or prevented. The strategies and solutions that these women devise can also provide a foundation for how government and other service providers tailor their care and craft appropriate responses (Kornelsen and Grzybowski, 2006). While many

women face constraints related to poverty and marginalization, they employ diverse responses to health care barriers.

This study presents findings from the rural Eastern Cape in South Africa about how pregnant women and new mothers navigate and respond to challenges in accessing health care during the perinatal period.

2. Methods

This study employs a qualitative research method, and was part of a larger study evaluating the Enable Mentor Mother program aimed at improving maternal and child health and nutritional outcomes amongst vulnerable households. Ethical approval was granted by the Health Research Ethics Committee at Stellenbosch University (N16/05/062).

2.1. The Enable Mentor Mother model

The One to One Children's Fund established the Enable Mentor Mother program in 2016 as the first “social franchise” of the Philani Mentor Mother home visiting model (further referred to as Philani). Philani first launched its program to address maternal and infant mortality and malnutrition in a peri-urban area outside Cape Town in the early 2000s. Enable's social franchise transported this model to a new rural area, under new management, with continued support from Philani (Laurenzi et al., 2019; Rotheram-Borus et al., 2011). Enable's Mentor Mother model looks for women who may be “positive peer deviants”—caregivers who have managed to raise healthy children despite adverse circumstances. Potential Mentor Mothers are identified by traditional or other community leaders, as well as through advertisements. After submitting curricula vitae, a subset of applicants are selected to participate in a six-week training with experienced trainers. Training includes content on building client relationships, antenatal and postnatal care and nutrition, infant care and nutrition, HIV/AIDS, and social support. Trainees are invited to become Mentor Mothers based on their geographic location, and if they successfully pass a written examination at the end of training. Mentor Mothers work in their own communities, identifying and enrolling pregnant women and malnourished children, and deliver health education, support, and referral services to clients in their homes. Fourteen Mentor Mothers were recruited into Enable's first cohort in 2016, and one subsequently was promoted to a supervisory role, leaving 13 Mentor Mothers working in the original program areas.

2.2. Setting

Enable's Mentor Mother program operates in a remote and rural part of Nyandeni Municipality (population 290,320) in South Africa's Eastern Cape Province (estimated population 6.5 million) (Statistics South Africa, 2011, Statistics South Africa, 2018). While South Africa's health system is characterized by stark differences in access and quality, the former “homeland” areas of the Eastern Cape have particularly poor health care outcomes. Nyandeni is situated within one of these areas, in the O.R. Tambo district, which has a maternal mortality rate well above the national rate (196.9 deaths per 100,000 live births, compared to the national 116.9) (Le Roux et al., 2015; Massyn et al., 2017). The O.R. Tambo was among the top 10 districts with the highest proportion of facilities reporting a medicinal stockout in 2017 (StopStockouts, 2017). Nyandeni Municipality has the lowest district-wide rates of early antenatal visit booking, with more than a third of pregnant women not completing antenatal visit before 20 weeks (Massyn et al., 2017). However, its inpatient early neonatal death rates are also well below the national average.

2.3. Recruitment

Participants were pregnant women or new mothers who had been

enrolled in the Enable Mentor Mother Program and were clients of one of Enable's 13 Mentor Mothers. To ensure a variety of different perspectives on the program and allow for geographic variation, an equal number of clients per Mentor Mother ($n = 2$) were purposively sampled from each Mentor Mother's caseload, which contained, on average, 30–35 maternal cases. The first author, CL, also checked that client characteristics varied by age and number of prior children. In cases where a potential participant was unreachable by phone, unavailable, or uninterested in participating, a backup participant sharing the same Mentor Mother was contacted instead. A number of clients initially contacted were temporarily working away from home ($n = 3$), were uninterested ($n = 1$), or were unreachable by the interviewer ($n = 8$) due to mobile network issues or a change to their contact number, requiring a backup participant to be contacted instead to reach the intended number of clients.

2.4. Data collection tools and procedures

Interviews were conducted from February–March 2018 by an isiXhosa-speaking research assistant, VN, with extensive experience conducting qualitative interviews. Interviews were guided by a semi-structured interview schedule. CL and VN met to discuss each question on the interview schedule to eliminate instances of ambiguity and revise the schedule for simplicity and clarity. The interviewer contacted potential participants, scheduled interview times, and visited each participant to conduct the interview in her home. The interviewer obtained written informed consent from all of the participants. Further, all of the interviews were conducted in participants' first language, isiXhosa. Throughout the two-month interview period, CL and VN discussed progress 3–4 times weekly, including individual interview highlights and challenges. Interviews were audio-recorded with permission from the participants. Interviews were, on average, 1 h each, with most interviews falling between 45 and 90 min' duration.

2.5. Transcription and translation

Interviews were transcribed verbatim and translated from isiXhosa into English. Transcription took place between April–October 2018. Two experienced isiXhosa-speaking transcribers listened to the audio recordings of the interviews, and transcribed the interview content using MS Word, translating directly into English. In some cases, specific words were left in isiXhosa to preserve their meaning (for example, traditional Xhosa beliefs/concepts about pregnancy). Alternative definitions were given as appropriate. A senior isiXhosa-speaking member of staff quality checked 50% of the transcripts for accuracy and determined them to be of high quality.

2.6. Ethical considerations

During informed consent procedures, the interviewer ensured that privacy and confidentiality were discussed, and that participants understood how their information would be used and were given the opportunity to ask questions. All consent forms were anonymized using a unique participant identifier, and this identifier was also used to label audio recordings, transcriptions, and data analysis files. The audio recordings were removed from the recording devices at the end of each day; they were first stored on a password-protected laptop in a locked room at the research site in Mankosi, filed by date completed and participant identifier, and later transferred to a cloud-based folder. This folder was used to securely transfer and complete the transcription and translation processes. Referral mechanisms were established in case of participant distress or additional challenges identified by the interviewer, but did not have to be utilized during the course of fieldwork.

2.7. Data analysis

Data were coded and organized using ATLAS.ti qualitative software. All transcripts were read and coded with a specific focus on data related to experiences of accessing health care, challenges in accessing care, and responses to these challenges, using an inductive coding method. While participants were interviewed as part of a larger study to explore their engagement with and perceptions of the Enable program, their experiences of accessing health care emerged as important aspects of these interviews. From an initial list of 98 codes inductively generated from the full participant interviews, 14 codes specifically related to accessing health care. Interviews were re-read with a closer focus on this particular aspect of the data, and an additional 14 codes were identified; thus, 28 relevant codes were ultimately identified regarding these experiences, challenges, and responses. This final code list was shared with a second coder, SG, who read and coded three transcripts. Double-coded transcripts were compared to ensure consistency. Themes and sub-themes, discussed with co-authors, were generated from grouping similar types of barriers and responses together.

3. Results

A total of 26 participants were interviewed between February and March 2018, representing two clients per Mentor Mother. Participants' mean age was 26.9 years ($SD = 5.77$), eight were married (30.8%), and 10 were first-time mothers (38.5%). 57.7% of participants had been enrolled in the Enable program during its first six months operating in Nyandeni (July–December 2016). The 28 codes identified in the interview transcripts were grouped into 2 themes and 4 sub-themes (Table 1). The majority of participants described accessing health care at one of two government clinics in the local area.

3.1. Responding to interpersonal barriers to care

Discussing interpersonal interactions in clinic settings, predominantly with facility staff, participants described a lack of communication that they had come to expect, and accept, as well as poor quality care tied to resource shortages and inconsistent procedures at clinics.

3.1.1. Passivity and acceptance in interpersonal interactions with health care staff

Participants were mindful of tacit patient-provider hierarchies as they spoke about adopting passive strategies to maximize their chances of being treated in a timely way, or at all.

PID2: I keep quiet ...

Interviewer: Mmm, are you afraid?

PID2: No, I'm not afraid, but I just want them to help me ... Because if I can express myself, I might go back [home] hurt ... I have to wait.

She later continued:

If you go there, you must be calm and relax, because you would feel like they are not paying attention to you because you are so many, others came for their own problems ... then you don't have to rush them, you must wait for them.

Table 1

Themes from participant interviews.

1. Responding to interpersonal barriers to care
1.1 Passivity and acceptance in interpersonal interactions with health care staff
1.2 Navigating interpersonal interactions more assertively
2. Responding to structural barriers to care
2.1 Frustration and hurt from repeated systemic failings
2.2 Troubleshooting and planning ahead

Returning home “hurt,” at not having been treated at all, was something that other participants raised concerns about. To some women, acceptance or “endurance” was part of the process of receiving care:

They do shout at us, but since we are women we endure, just if she is shouting at you but doing it for you (PID21).

While participants articulated the challenges and mistreatment they encountered, and the consistent frustrations experienced during clinic visits, they also chose to defer to health care providers and wait their turn.

Some participants adopted a more accepting approach to barriers to care, sharing various reasons for this decision. Often, they attributed poor interpersonal engagement from health staff to larger health systems issues that those staff faced. Participants said they fully expected clinic visits to be a daylong commitment, and some explicitly lamented “there is nothing you can do” (PID11). Most participants’ days began with time-intensive travel to the clinic, “then when you get there, you sit for long and be told to wait, wait, and wait, you will be waiting for long” (PID20). Some participants accepted the limitations facing their clinics and staff, sharing a degree of sympathy once these challenges were communicated to them. Noting that clinics tend to be out of stock on a regular basis, one participant noted:

PID25: They say ... but, shame, they do explain to us, they say that they order treatment while they still have [it] in stock and then it would delay, a day or 2 weeks or 3 weeks without it.

In other cases, health providers were less communicative and less systematic. Another participant described how nurses operating alone often had to choose one group to start with:

Maybe a nurse may come, for example the one that works with children. She weighs, she immunizes and does antenatal care all alone, then maybe the nurse would say “no I’m going to start with those who are pregnant, new mothers must wait” or say “I’m going to start with new mothers.” Clinic procedure does not depend on time, it does not matter even if you woke up in the morning or not (PID3).

The act of showing up at the clinic did not guarantee that an individual would receive care; participants mentioned that this was often left to chance, or just “how things work,” and indicated that there was limited action they could take to change this situation.

3.1.2. Navigating interpersonal interactions more assertively

3.1.2.1. Empowerment and education as important tools. Other participants adopted responses that were more direct, electing to resist or make their voices heard, and spoke about the impact of education and awareness of their rights. A young mother who spoke of nurse mistreatment shared:

They [nurses] have that belief of they can treat people in any way, the way she likes You would find out that some people are not able to oppose what they are saying. So when I grew up, I realized that I cannot tolerate that (PID11).

This approach was not common for most participants, and this particular woman cited her higher education and self-confidence as playing a role in advocating for her own health needs. Other experiences illustrated participants’ sense of empowerment in clinic-based interactions based on routine home visits with their Mentor Mothers.

PID18: The difference is, sometimes when they are telling me something at the clinic, they tell me things that I know already [from my Mentor Mother] ...

Interviewer: Okay, so you go there already with your information?

PID18: Yes.

To some, having the additional support of a Mentor Mother became a way to better understand the information given to them at clinic, and also equipped them with information that they might use to question and engage health workers. This participant spoke about complaining to a nurse about being overlooked, and noted: “Obviously, it can’t be not heard when you are angry” (PID18). Participants’ communication strategies also included drawing attention to urgent health needs, especially in cases when the health facility staff was taking a break:

You must shout if your child is not okay ... up to a point [where] even someone who is passing by the road can hear (PID1).

Drawing on their own education and tested strategies, as well as on additional Mentor Mother support, participants described assertive strategies for being helped.

3.1.2.2. Special relationships as a means to receiving care. Other participants indicated that the best way to access care was through being “known by” (PID18), or “hand in hand” with a nurse (PID2). Seeing a system that did not serve its patients equally or with care, these participants stated that existing personal relationships with clinic staff sometimes worked in patients’ favor, having experienced this personally or observed it with other patients. Additionally, as clients of the Enable program, some participants described the tangible impact of having a Mentor Mother to facilitate referrals for special cases. One participant said, of her Mentor Mother, “you cannot end up dying in her presence” (PID2), indicating that having a Mentor Mother meant having access to necessary care and attention regarding important health needs. Having a referral in-hand often meant readier access to care for participants.

Interviewer: When [your MM] writes you this letter, does it help you when you go to the clinic? For example, the nurses—are they not saying, “where did you get this letter?” and so on and so forth?

PID12: No, they would look at it and ask which Mentor Mother gave me this ... who gave me this, and I would tell them I got it from my Mentor Mother called [MM name], then it would be signed, then they would ask me about the pains I am feeling.

The additional support and treatment that participants cited—whether through nurse familiarity with Enable, or through personal connections—conferred a sense of empowerment, enabling them to access further channels for recourse when facing routine health barriers.

3.2. Responding to structural barriers to care

In addition to sharing interpersonal challenges during clinic visits, participants described substantial barriers to receiving quality care related to structural shortcomings.

3.2.1. Frustration and disappointment from repeated systemic failings

Many participants shared feelings of disappointment, as well as diminished motivation to seek health care, after not receiving adequate services. Structural barriers, such as 2-h trips on foot to the nearest clinic, compounded these systemic failings. Speaking about medicinal stockouts, a participant labeled these regular occurrences as displaying “carelessness from the government,” asking, “they know the life of that person depends on that treatment, so how can they not have treatment?” (PID25). These responses were exacerbated when participants took initiative by keeping track of required immunization dates, or had an ill child needing medicine, and were not sure whether or when they would be able to afford a second trip (PID17).

You just feel disappointed, having no interest to get back there again, because even that time you will be going there to check, not knowing if [immunizations] are available (PID6).

Participants also spoke about feeling unrewarded for their efforts such as taking a day off work to attend clinic for her child's immunizations:

When I decided to go on that day, I would have told myself that day is for the clinic ... maybe I would be busy on the day they say I must go [return again], it is worse [harder] that I am here [working] at the creche now, I would have asked permission for that certain day (PID7).

Participants also conveyed how these experiences restricted their choices, or their ability to act in their own or their child's best interests. While stockouts were common reasons for not receiving needed care, participants who required more comprehensive clinical care also struggled to move between facilities because of lack of funds:

I do not want to lie, it was when I was still pregnant, I was in pain, I went to the clinic and when I got there, they wrote me a letter to go to [the hospital] and I did not have money to go ... I came back home sister, I did not go because I was borrowing money and I was not getting [earning] money and there is no other way because from here to [the hospital], it is R20. So I couldn't, sister, because of that (PID10).

Another participant spoke about “just losing power” from repeatedly frustrating experiences, which made her less inclined to attend the next given date; she explained that she might, in response, take her time and “go there on my own date that came to my mind” (PID21). Some participants relayed stories—their own or their neighbors’—when they did finally attend clinic after a scheduled visit and were summarily reprimanded for their tardiness.

3.2.2. Troubleshooting and planning ahead

While many participants took stockouts and onwards referrals personally, there were other participants who sought to circumvent structural challenges in other ways. They adopted problem-solving approaches, focused on preparation with the understanding that many other aspects of seeking care were out of their control. To ensure they were able to return to clinic when it was next required, participants found various ways to set aside money for transport:

If I know that this week is my appointment date ... I keep the money for myself, know that I have this date, on the 15th I need to go to the clinic. If perhaps if I had money on the 12th, I will keep it for myself, then I will go to the clinic with money for lunch and travelling (PID26).

Another participant said that she sometimes relied on her mother to help her cover the cost of clinic trips (PID14). While not every participant was able to problem solve in these ways, these women were able to improve their odds of receiving much-needed preventative care by having some social support as a means to gain important access to financial and emotional support.

Facing recurring stockouts, some participants spoke about adopting more flexible approaches: stocking up on essential medicines from the pharmacy, or linking with other neighbors to procure medicines. Often, these experiences were communicated as hypotheticals to the interviewer:

Sometimes if my child is sick now ... and the clinic is far away when I'm here, there is no transport and I'm here ... what am I going to do? I have to take those medicines and help her in the moment (PID24).

Walking through a set of options, another participant described her reasoning:

PID26: If there are no medicines this week, you will stay and come back another week or buy yourself at the chemist [pharmacist].

Interviewer: If you don't have money for chemist?

PID26: If you don't have money for chemist, there is a[nother] clinic this side ... We also go there, however they don't run out of them for long time here, they have them, but when they happen not to have them, we cross to

that clinic.

Citing how far town was, another participant said if she were desperate to get her child's medicine, she would ask a neighbor or acquaintance headed towards town to help (PID3).

Lastly, relying on community networks in a different way, participants spoke about using their Mentor Mothers as a communication channel to access care more readily. One participant noted that if a mobile clinic was scheduled to be in her area, her Mentor Mother would phone her or her husband and indicate what time they should be ready and where they should go to improve chances of her baby receiving timely immunizations (PID5). Having a Mentor Mother to both inform and motivate this participant allowed her to access alternative forms of health care more easily.

Although participants were not able to fundamentally change the nature of the problems they faced, they shared methods for coping in ways that increased their chances of better health outcomes.

4. Discussion

The barriers and challenges that pregnant women and new mothers face in accessing care have been well documented in LMIC settings; however, less is known about how women respond to these challenges. We set out to understand the health access experiences of pregnant women and new mothers in a remote, rural part of South Africa—and more importantly, to gather perspectives on how they individually navigate and respond to barriers to health care access. Participant responses at both interpersonal and structural levels reflected diverse modes of navigating persistent barriers, yet also revealed an ongoing struggle to maintain motivation in the face of these challenges.

These findings illuminate the extent to which individual women engage in a broad range of strategies to cope and maintain dignity in the face of a health system that does not consistently serve them. They reflect similar themes to the case stories presented by Eyles et al. (2015), where South African health-seekers and providers alike detailed narratives of endurance, resilience and resistance (Eyles et al., 2015). However, importantly, our findings also expose a level of exhaustion, disenchantment, and lack of trust in an institution established to provide equitable care in addition to (and in spite of) participants' navigating and strategizing. As ongoing global initiatives attempt to improve the quality of maternal and newborn care, as a means to ensure dignity and equity for all women (Organization, 2018b), these considerations are even more important. By paying attention to what women are already doing in this realm—to weigh their best chances of accessing services, and being seen and treated—we can begin to understand the complexity of their experiences and how to best frame policies for improving equity.

Other recent literature from South Africa helps put these findings in context. Passivity in patient-provider interactions is common in a traditional, paternalistic model of medicine (Kaba and Sooriakumaran, 2007). Such interactions are commonplace in rural settings in South Africa in particular, and may be driven by a lack of external or community-driven accountability mechanisms (Berlan and Shiffman, 2011; Cleary et al., 2013), poor supervision and leadership to drive quality care (Maphumulo and Bhengu, 2019), health worker burnout (Khamisa et al., 2017; Nesengani et al., 2019), and low health literacy (Safiya et al., 2009). For rural women, especially in the former “homelands”, hierarchies between patient and provider have been reinforced through the re-engineering of district-level primary health care (van Ginneken et al., 2010). It has been argued in these contexts that a “covert contract” exists, where patients adopt the idea that they need to be a “good” patient (Frosch et al., 2012; Joseph-Williams et al., 2014), who does not question advice or actions of a health professional. Often, authoritative approaches from health providers, who may not engage patients in decision-making or attempt to use the encounter to support patients, can set the tone for unequal interactions. Other research has

shown that providers may struggle to prioritize sensitivity in clinical encounters when there are more pressing structural concerns (Bhattacharyya et al., 2015). Likewise, from participant perspectives, “enduring” was seen as a default response. Many women did not see themselves as able to demand better care, further entrenching power divides between patients and providers as patients simply accept and “endure.”

We found that some women responded to both interpersonal interactions (e.g., facing poor treatment from health providers) and structural failings (e.g., experiencing repeat medicine and/or immunization stockouts) with a diminished motivation to return to clinic. Other literature echoes these themes, with women who have experienced punitive treatment by health providers at clinics—for skipping appointments, for example—voicing a reluctance to seek care (Foster et al., 2010; Honikman et al., 2015; Munguambe et al., 2016). For some women, the financial cost of multiple return trips to check on medication stocks is not viable (Bedwell et al., 2017). These responses, while they may be a result of higher-level shortcomings, reinforce health inequities by decreasing the number of health contacts for mother and child and disincentivizing the effort needed to receive adequate care.

The range of responses shared could also be framed as reflecting emotion-focused and problem-focused coping (Lazarus and Folkman, 1984). This model, devised by Lazarus and Folkman, differentiates coping responses to stress as either focusing on managing the emotions associated with the stressor, or tackling the underlying problem causing that stressor. Some participants’ responses were linked to personal feelings, especially when they faced recurring challenges: reflecting on these experiences was a way of sharing underlying frustrations that they felt unable to effectively change. Other women embraced more active, problem-based coping mechanisms, by attempting to prepare for adverse circumstances, or carrying out small acts of resistance. Some participants specifically mentioned the instrumental function of their Mentor Mothers, facilitating access to immediate care or identification of a health problem in a way that had not been previously possible. However, overall, problem-based tactics were often more restrained. Unable to seek further care because of financial constraints, women spoke of returning home empty-handed; unable to be seen and treated as individuals in an overburdened clinic, many opted to stay quiet or “endure” instead of openly defy a health provider. While participants described finding small ways to “gain power,” it is important to recognize that not all were able to channel this approach. Importantly, a number of participants detailed both types of responses.

While South Africa’s health system is rooted in a history of fragmentation and inequity, other similar countries, such as Brazil, have found success in integrating the public health system to be more aligned with the needs of poor communities (Jurberg, 2008). Brazil’s primary health care-focused Family Health Strategy utilizes health teams including one physician, one nurse, one nurse assistant, and up to six CHWs, which serve pre-defined catchment areas (Andrade et al., 2018). Despite variability in health-seeker experiences, studies gathering patient perspectives have found generally high satisfaction with geographical accessibility, acceptable services, and interpersonal interactions (Fausto et al., 2017; Gaiosio and Mishima, 2007). Although CHWs such as Enable’s Mentor Mothers can provide motivation and social support for pregnant women and new mothers who may struggle in accessing routine care, they operate as an add-on to the government health system rather than an integrated part of it. As such, Enable still relies on a separate functioning health infrastructure to accomplish program goals, unable to replace formal health services (Tulenko et al., 2013). For programs designed to connect clients to resources, expand health education, and promote uptake of safe preventative health practices, an absence of adequate services, as well as structural barriers to accessing formalized health care, can limit the scope of these program goals, or render them unattainable (Blacklock et al., 2016; Kok et al., 2015).

4.1. Implications of these findings

Our findings highlight both interactive and active responses by pregnant women and new mothers as they faced considerable challenges in accessing care for themselves and their infants. Making women more aware of their health rights is a central part of confronting these persistent challenges, however, these efforts must take place within a broader enabling environment. These findings illustrate the need to prioritize supportive patient-provider interactions in clinical settings, and to integrate these interpersonal approaches with more innovative solutions that can increase access to care. Promoting principles of shared decision-making in pre-service and ongoing clinical training, which is well-theorized and researched between doctors and patients, could be an important first step, with primary health care professionals encouraging and preparing patients to actively participate in the clinical encounter (Joseph-Williams et al., 2014). This approach has been shown to improve patient satisfaction, preserve a sense of patient dignity and autonomy, and reduce the burden on the physician (Schain, 1980). Women’s satisfaction has been found to be correlated with provider empathy in low-income settings, especially among women who recorded experiencing birth complications (Bazant and Koenig, 2009). This speaks to the importance of recognizing that across all contexts, interpersonal aspects of care should be emphasized equally alongside structural improvements. However, this approach necessitates equipping health providers with the necessary skills and competencies to supportively engage patients at all stages of the medical encounter and provide empathic professional services. Improving provider communication skills and giving space for patients to provide feedback may enhance the quality of care, even in overstretched health facilities (Pantoja et al., 2017).

On a more immediate level, for CHW programs in LMICs in particular, it is imperative to establish strong linkages between these types of programs and existing primary health care infrastructure. In the foundational work that happens before pilot programs are implemented, or successful models are taken to scale, targeted communications with locally-embedded health facility management are essential. Lastly, mobile clinics may be an important bridging mechanism, delivering health care services to remote communities and making services more accessible for the most vulnerable who may struggle to travel to bricks-and-mortar clinics (Yu et al., 2017).

4.2. Limitations

By virtue of our participants’ inclusion in a home visiting program, they are not necessarily the most vulnerable—they ostensibly have more available support and a better grasp of relevant, essential health information. However, their experiences reflect typical health care experiences of women of childbearing age in their setting as corroborated by programmatic staff and co-residents. For this reason, they are central to providing a more detailed picture of patient perspectives and how health care services in remote places operate. Further research disentangling barriers to care might encompass interviewing a larger sample of women, or incorporating a more detailed observational or ethnographic data collection effort recording barriers to care across a range of methods, such as journaling or case note/record review.

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Author statement file

CL conceptualized the study, oversaw data collection, transcription, and translation, coded all transcripts, and wrote the first draft of the paper. SG provided quality control for the coding of transcripts and also

offered important feedback on the drafts of the paper. VN co-designed the interview guide with CL, conducted all interviews, and provided valuable input to the methods and discussion sections. BC, SS, and MT offered critical conceptual and technical feedback to the study design and writing of the paper. All authors read and approved the final manuscript.

Declaration of competing interest

None.

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